Predictors of primary health care utilization by former residents of institutions in Ontario

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Submitted in partial fulfillment

of the requirements for the degree of

Masters of Arts

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St. Catherines, Ontario

Abstract

For years institutionalization has been the primary method of service delivery for persons with developmental disabilities (DD). However, in Ontario the last institution was closed on March 31, 2009 with former residents now residing in small, community-based homes. This study investigated potential predictors of primary health care utilization by former residents. Several indirect measures were employed to gather information from 60 participants on their age, health status, adaptive functioning level, problem behaviour, mental health status and, total psychotropic medication use. A direct measure was used to gather primary health care utilization information, which served as the dependent variable. A stepwise linear regression failed to reveal significant predictors of health care utilization. The data were subsequently dichotomized and the outcomes of a logistic regression analysis indicated that mental health status, psychotropic medication use and, an interaction between mental health status and health status significantly predicted higher primary health care usage.

Acknowledgements

I would like to thank my family for their encouragement and support throughout this entire process. I would also like to thank Dr. Rosemary Condillac for her superior guidance and mentorship. My sincere gratitude goes out to the volunteers and research assistants in the Facility Initiative lab for their assistance in data collection and entry. This work could not have been completed without the excellent statistical guidance that Dr. Jan Fritjers provided. To my friends, for providing fabulous, fun-filled distractions throughout this process; and to Kevin Graham for his patience, love and endless encouragement.

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Introduction

In 1867 Ontario's governmental agencies began to take on the responsibility of supporting individuals with Developmental Disabilities (DD) in large institutions. The institutionalization of persons with DD came to be seen as a way to protect its residents from the ills of society and to provide for them (Walmsley, 2006). Moreover, this method of service delivery meant that residents received primary medical care from professionals employed by the institution or government. These physicians' sole responsibilities included tending to in-patient health and mental health care needs. This method of service delivery was in place for approximately 150 years however, alternatives to institutionalized methods of residential and health care began surfacing in the 1950's (Bruininks, Kalda, Hauber, Hill, & Wieck, 1981). This was in part due to the fact that research investigating the effects of institutionalization found evidence of client losses of adaptive behaviour over time, unethical treatment and high resident mortality rates (Larson & Lakin, 1989). Parents and other advocacy groups began lobbying the government to provide community-based services (Radford & Park, 1999). Moreover, the complete replacement of institutions by services in the community was articulated in 1972 (Radford & Park, 1999). An intensive process followed, whereby, family members, policy-makers, professionals, and lay persons alike worked to promote a new era of service delivery for persons with DD, through various legislative changes, research, and lobbying efforts (Angline & Braaten, 1978). This movement saw the dramatic expansion of community care options (Larson & Lakin, 1989). In 1984, the first Ontario institution for persons with DD closed (Radford & Park, 1999). This marked the beginning of deinstitutionalization in Ontario. Several waves of closure followed. The final wave of

closures was announced in the fall of 2004, and was called the Facilities Initiative. The last institution in Ontario closed its doors as of March 31, 2009.

While the deinstitutionalization movement continues to gain momentum in North America, the controversy surrounding it has intensified. This is in part due to the 'normalization' principle which emphasized the central importance of providing systems and lives that are as close to 'normal' as possible for persons with DD (Nirje, 1969). A critique of normalization is that it implies that movement out of an institution will automatically improve all aspects of a person's life (i.e., adaptive behaviour, maladaptive behaviour, community integration, level of activity, satisfaction, staff interaction, quality of life (QOL), choice-making and mortality) simply because of a change in environment (Wolfensberger, 1980). Some family members of residents vehemently opposed the process of deinstitutionalization, out of concern for the capacity to support these individuals in community settings. For example, Tabatabainia (2003) conducted semi-structured interviews with 22 families of former residents to inquire about their thoughts concerning deinstitutionalization and institutionalization. The themes surrounding opposition to deinstitutionalization included: i) inadequacy of community-based residential services, ii) adverse effects on former residents' lives, and iii) the belief that the institution their relative resided in provided good service. Further themes emerged including fears about inappropriate programming and supervision and fears of incompatibility with fellow housemates. Moreover, contentedness with the resources (e.g., medical care) currently made available through the institution was a primary theme highlighted. Feelings of guilt were also noted by some families who had been told by professionals that their relative would not succeed in the community many years before

these families had made the difficult decision to place their loved one in an institution (Conroy, 1985; Chenoweth, 1998).

Some benefits to living in smaller, community-based residences have been documented. These include: i) greater access to social and leisure activities (Hundert, Walton-Allen, Vasdev, Cope, & Summers, 2004; Kozma, Mansell, & Beadle-Brown, 2009), ii) increased opportunities to contribute meaningfully to society (Kozma, et al., 2009), iii) more opportunity for choices in day-to-day living activities (Kozma, et al., 2009), and iv) more opportunity to take part in local community life (Baker, 2007; Kozma, et al., 2009).

Other researchers have reported inconsistent findings regarding the impact that relocation has on former residents' problem behaviours (Kim, Larson & Lakin, 2001; Stancliffe, Hayden, Larson & Lakin, 2002), psychotropic medication use (McGillivray & McCabe, 2005; Nottestad & Linaker, 2003), and utilization of primary health care services (Lennox, Nadkarni, Moffat & Robertson, 2003; Nottestad & Linaker, 1999; Tyler & Bourguet, 1997), to name a few.

The base of literature investigating community-based primary health care utilization by individuals who once resided in a facility but now live in the community is much smaller than the broad base of literature on the effects of deinstitutionalization. Some of the health care studies have defined health care access as both the receipt of services and the potential for obtaining appropriate health care services, in that the terms 'access' and 'utilization' were used interchangeably (Bhaumik, Tyrer, McGrother, & Ganghadaran, 2008; Porisky & Minnes, 2009). Other studies have defined access as the accessibility of services (Hayden, Kim, & DePaepe, 2005; Sowney & Barr, 2004) and

utilization as the uptake of these services (Lennox et al., 2003; Lin et al., 2007). The current study employed the latter terminology. Specifically, the term utilization was used to describe the actual use of health services (the participant has had direct contact with a primary care physician). In order to contribute to our knowledge base and to inform interested parties in other jurisdictions who have yet to begin this process, this study was designed to examine the predictors of health care utilization for some former residents of Ontario's institutions.

There are several important reasons for pursuing research in this area. First, the literature regarding specific patterns of primary health care utilization by former residents remains scarce. Authors of existing literature have encouraged further examination of potential relations between individual characteristics and primary health care utilization (e.g., Hayden et al., 2005; Levy et al., 2006; Pruncho & McMullen, 2004). Therefore, additional investigation would contribute to our knowledge and add to the currently limited research base. Second, this research would serve to address some concerns raised by family members and care providers who worry about health care service gaps in the community (Tabatabainia, 2003). Third, within the institution there existed a centralized system of delivery and most services were acquired therein. Currently, it is unknown as to whether the same level of care can/has been maintained by former residents living in the community.

Implications for findings

Persons with DD have repeatedly demonstrated a heightened need for primary health care utilization when compared to the general population (Wilson & Haire, 1990). This notion is based on findings that have indicated: i) elevated rates of medical

conditions/illnesses (van Schrojesnstein Lantman-DeValk, Metsemakers, Haveman, & Crebolder, 2000), ii) psychotropic medication use (Aman, 1984; Clark, 1997), iii) mental illness (Deb, Thomas & Bright, 2001a), and iv) inadequacy of knowledge of attention applied by community-based physicians (Lennox, Diggens, & Ugoni, 1997). As such, if the results of this study indicate lower levels of health care utilization than recommended by Sullivan et al. (2006) this poses a serious problem as it places former residents at a greater mortality risk and may ultimately affect their overall quality of life.

Benefits of isolating predictors

In a previously published study, Feldman, Atkinson, Foti-Gervais, and Condillac (2004) found that over 50% of persons with DD in Ontario engage in problem behaviours such as aggression, self-injurious, stereotypic or disruptive behaviour. Some researchers have found that former residents often continue to exhibit problem behaviours within their new community home (Nottestad & Linaker, 1999; Nottestad & Linaker, 2002). The continued presence of this behaviour is specifically problematic. Preliminary research findings have suggested that problem behaviours may directly impact utilization of primary care (Lennox et al.,1997). It is important that the relationship between problem behaviour and health care utilization be investigated to determine how to best serve this population. Moreover, other associations between a number of variables and service utilization have been identified (Lennox et al., 2003; Lewis, Lewis, Leake, King, & Lindemann, 2002; Levy et al., 2006; Lin et al., 2007). Identifying predictors would allow for the creation of a profile of higher or lower primary health care users. This may be used to enhance utilization and inform the development of service delivery in the community.

Implication of findings for families, service providers, and policy makers

Uncovering potential shortcomings in primary health care utilization may promote awareness and encourage policy makers to develop reasonable solutions to remedy issues as quickly as possible. On the other hand, if service utilization is found to be optimal, it may provide a great sense of relief to family members and those charged with the care of former residents. Finally, documented physician shortages in Ontario (Canadian Broadcasting Corporation News [CBC News], 2006) may or may not impact upon the primary health care utilization of former residents. The deinstitutionalization process has resulted in the reallocation of medical duties from institution-based to community-based physicians who often have limited training to support individuals with DD and limited time in which to provide this support. Moreovoer , many health care professionals are currently operating at capacity. Given the circumstances, the outcomes of this study may indicate whether or not this shortage impacts former residents and will ultimately serve to further inform policy makers in decisions regarding primary health care utilization for former residents.

Literature review

This study was designed to examine the predictors of health care utilization by former residents of institutions in Ontario. This section is structured to review the existing research on this topic as well as what is known about predictors to date. It will also provide a comprehensive review on the relationships between participant individual characteristics and their potential predictive capabilities on health care utilization.

Utilization of community-based primary health care

A majority of the deinstitutionalization literature suggests improvements in quality of life occur for residents after moving to community settings (Ashaye, Fernando, Kohen, Mathew, & Orrell, 1998; Emerson & Hatton, 1996; Stancliffe & Lakin, 1999). However, Krahn, Hammond, and Turner (2006) have also indicated ongoing concerns about unmet health care needs. Specifically, these researchers reviewed health care utilization literature that was conducted in the United States (US) from 1999 to 2005 and highlighted several themes such as persons with DD experience poorer general health than the general population and inadequate access to quality health care services, among others. Moreover, Howells (1986) presented findings from the United Kingdom (UK) that indicated only 28% of participants who attended the day center in the study had adequate contact with their general practitioner (GP). Wilson and Haire (1990) further supported these conclusions when they investigated the prevalence of prescription medication regimes and corresponding rates of GP contact by persons with DD living in the UK. Although the living arrangements of these participants varied from state institutions to group homes to one client living independently, it was found that 43% of the participants were taking psychoactive medications. Only 39% of those participants

taking psychoactive medications had their medication reviewed prior to renewing the prescription. Additional findings revealed that 24% had not seen their physician in over a year, despite the fact that a majority of the participants were on prescription medication (Wilson & Haire, 1990).

Conversely, Minihan and Dean (1990) surveyed the health needs of a large sample of participants living in southeastern Massachusetts, who were randomly selected from a population of persons with DD living in a range of settings; approximately one-third of their participants had been deinstitutionalized. Their results indicated that 87% of participants had a regular primary care physician. Sixty-two percent of participants were judged to have one or more chronic medical conditions serious enough to warrant ongoing medical intervention. Age and gender influenced the type of physician (e.g., primary care, psychiatrist) and how often a participant saw this professional. For women, preventative care was deemed problematic as only 40% of participants had received a gynecological exam however, the researchers concluded that the vast majority of health conditions listed by their participants could and were being managed within the community health care system.

More recently, Havercamp, Scandlin, and Roth (2004) reported lower health care utilization trends in North Carolina by people with DD living in the community. These researchers investigated differences in health care service utilization between participants with DD and those without DD. All individuals with DD who participated in the study were living in the community. Some resided in group homes, others with family members and a few lived independently. The results found significant differences regarding breast and cervical cancer screenings, whereby preventative health care utilization rates were

much lower by persons with DD than by the other two comparison groups. This finding is indicative of preventative medical care shortfalls. Hall, Wood, Hou, and Zhang (2007) reported further problems with utilization in Florida. Their findings indicated that about 40% of their participants did not see a primary care physician over a period of four years.

Fisher (2004) reviewed the literature regarding patterns in health care utilization for persons with DD in order to examine the current status. The articles included in the review had been conducted in Canada, Germany, the Netherlands, Sweden, the UK, and the US. She found that individuals with DD have an increased prevalence of certain health conditions (e.g., thyroid disease, seizure disorders, obesity, ocular anomalies, and poor oral health), however, these same individuals were less likely to receive adequate medical services compared to those in the general population. Based on her findings, she suggested that relatively little is known about the *quantity* and *quality* of health services that people with DD receive (Fisher, 2004).

Prevalence of health problems in individuals with developmental disabilities

A number of studies support the common belief that persons with DD are more likely to have health problems than the general public. For example, Minihan and Dean (1990) found that in their sample of 333 persons with DD in Massachusetts, two-thirds had chronic conditions requiring medical intervention. A study conducted in the Netherlands by van Schrojesnstein Lantman-DeValk et al. (2000) specifically noted that individuals with DD had twice as many health problems as individuals without DD when comparing the health status of 318 people with DD to a group of 48, 459 people without DD. More recently, Havercamp et al. (2004) compared data on health status, health risk behaviours, chronic health conditions, and utilization of medical care across three groups

of adults: those with a disability, those without a disability and those with a DD in North Carolina. They reported that persons with disabilities and DD were more likely to report being in fair or poor health than those without a DD who were more likely to report being in good health. Moreover, adults with DD had a greater risk of having four or five medical conditions compared to those without DD. Wilson and Haire's (1990) investigation was a little different in that they did not run a comparative study. Instead their results focused on undiagnosed health conditions in adults with DD in the UK. They found that 88% of their participants had a least one health problem that was undiagnosed prior to having conducted their study.

There is some suggestion in this literature that individuals with mild DD may share similar life expectancies with the general population, whereby Patja, Iivanainen, Vesala, Oksanen, and Ruoppila (2000) conducted a 35-year nation-wide follow up study in Finland. There were 2366 participants included in the study, both the general population and those with DD. This comparative study revealed that for people with mild DD, life expectancy did not differ from that of the general population. Conversely, for those with severe DD, life expectancy rates were much lower. In fact, mortality rates were investigated by Tyrer and McGrother (2009) in the UK. These researchers found that the overall mortality rate in their adult sample of persons with moderate to profound DD was almost three times as high as that in the general population. Congenital abnormalities were reported as the most common cause of death, followed by respiratory infections, cerebrovascular disease and diseases of the genitourinary and digestive systems. Ouellette-Kuntz (2005) conducted a literature review using research from Australia, Canada, the Netherlands, New Zealand, the UK, and the US. Her results

indicated that life expectancy for persons with severe DD is substantially lower than that of the general population. It is therefore important to note that functioning level may differentially impact health status and thus utilization patterns.

Although researchers have claimed that studies aimed at determining the health status of persons with DD compared to the general public are fraught with complexities and methodological issues, the fact remains that most studies investigating this topic have indicated higher rates of medical conditions in persons with DD than in the general population (Beange, McDuff, & Baker, 1995). This clearly punctuates the need for primary health care for people with DD and suggests that utilization rates should be higher than what is expected in the general population.

Individual characteristics and primary health care utilization

Age and primary health care utilization.

Age may impact health care utilization of adults because as an individual gets older more screening procedures and other protocols are required to maintain good health (e.g., mammogram, PSA tests) (Havercamp et al., 2004). However, research into preventative care utilization for adults with DD suggests that utilization of these services is low (Lewis et al., 2002). Moreover, Levy et al. (2006) investigated disability characteristics and medical conditions (e.g., health status) to better understand the relationship between these variables and patterns of health care utilization by persons with DD living in New York. The authors included age in their analysis. Although no significant relationship between health care utilization and age was evident, medical conditions and age positively correlated with one another. While a direct relationship between age and primary health care utilization in former residents is not often found, the fact is that this individual

characteristic is almost always included in the analysis in some form, it is either controlled for or used as a predictive variable.

Adaptive functioning level and primary health care utilization.

Adaptive behaviour refers to a persons functioning within their daily context and tends to include communication skills, activities of daily living, and social repertoire. There is a dearth of research investigating the relationship of adaptive functioning to health care utilization, though it is clear that functioning level is related to health and mortality (e.g., Tyrer & McGrother, 2009). Adaptive behaviour is often the focus of a large portion of the deinstitutionalization research comparing pre and post levels of functioning. However, inconsistent outcomes are reported repeatedly. For example, Bowen and Gerry (1995) conducted research in New South Wales and reported no discernable difference in adaptive behaviour after their participants had moved into the community from the institution. Similarly, Cullen et al. (1995) also reported generally modest changes, if any, after the participants had moved out into various community-based residences in Scotland. Conversely, O'Brien, Thesing & Tuck (2001) conducted research in New Zealand with 61 former residents, many of whom had spent over 22 years in the institution and had been living in the community for at least 9 years. The authors reported an overall increase in adaptive functioning.

Cooper and Bailey (2001) investigated the relationship between mental illness in adults with DD and level of adaptive functioning. Two hundred and seven adults with DD living in community-based homes in Leicestershire, UK participated in the study. It was found that those with severe DD had higher rates of mental health problems, over and above their DD. By emphasizing the relationships between individual characteristics,

the complexity of predicting primary health care utilization becomes apparent. As with age, the deinstitutionalization literature consistently uses functioning level in its analyses. Although specific relationships to health care utilization are not reported as frequently, they often play a large role as a control variable (Hall et al., 2007; Lewis et al., 2002; Levy et al., 2006). For example, Lewis et al. (2002) controlled for level of DD while completing a logistic regression analysis. Moreover, these researchers reported a significant association between functioning level and health status, whereby those with profound DD had the lowest Body Mass Index scores. Further, Patja et al. (2000) found that life expectancy was lower for people with more severe DD than those with milder DD.

Health status and primary health care utilization.

Change in health status after deinstitutionalization is scarcely mentioned in the literature. Research attempting to uncover patterns of primary health care utilization by individuals with DD in the community often includes health status as a variable of interest, yet it has not been explored for former residents of institutions. Lin et al. (2007) conducted a study investigating predictors of health care utilization by persons with DD living in various community-based homes in Taiwan. They found that health status significantly predicted utilization. Though the health care in this study was in-patient rather than out patient services, it can still inform our understanding of utilization patterns and how health status may impact them. Moreover, Hall et al. (2007) conducted a study to describe patterns of primary care utilization among adults with DD living in a variety of community settings (e.g., with family, group homes and/or supported living) in Florida. Through a regression analysis they discovered that those with a co-existing medical condition (e.g., spina

bifida) were more likely to have primary health care visits. Conversely, Fisher (2004) reported themes, which indicated that those with a higher prevalence of health conditions were less likely to receive health care. The previous information provides plausible reasoning that health status may differentially impact primary health care utilization rates. For example, an individual suffering from several medical conditions (e.g., poorer health status) may require more visits to their health care professional in order to treat their various ailments. On the other hand, conflicting research results have suggested that an individual with DD who suffers from poorer health status may be less likely to visit their physician. These studies support the premise that health status may impact primary health care utilization.

Problem behaviour and primary health care utilization.

Almost 50% of people with intellectual disabilities in an Ontario sample demonstrated problem behaviours (Feldman, et al., 2004). The results of this study indicated that the severity of behavioural issues were associated with the level of restrictiveness of the environment, with institutions representing most restrictive. Although some developed nations have mandated deinstitutionalization, research findings do not unanimously report improvements in problem behaviour after relocation. For example, Nottestad and Linaker (1999) compared the frequency of behaviour disturbances before and after deinstitutionalization. The individuals who participated in this study included all of the residents in a specific central institution in Norway that was scheduled for closure. Due to the pending closure a control group could not be included. The researchers, using the same data collection measures, gathered client information in 1987, one year before relocation, and again in 1995, one year after relocation. They concluded that there was a

significant increase in residents who attacked others, jumped and yelled and demonstrated passivity. In fact, 23% of participants had reportedly acquired behaviour disturbances after relocation even though living conditions had improved. Based on their findings the authors suggested that challenging behaviour is not a product of institutionalized environments and therefore, cannot be remedied simply by transfer to the community.

To further complicate the matter, studies have also reported no differences in problem behaviour based on living arrangement (Conroy, Efthimiou, & Lemanowicz, 1982; Cooper & Picton, 2000; Rawlings, 1985). For example, Lowe, Felce, Perry, Baxter, and Jones (1998) compared problem behaviour rates between family homes, group homes, community housing and hospital and hostel residences in the UK. Assessments of problem behaviour showed the people in the groups to be similar and to have a considerable range and extent of severely problematic behaviour.

Larson and Lakin (1989) conducted an extensive literature review on the impact of deinstitutionalization on former residents living in the US. Their findings add further support to the highly variable nature of problem behaviour outcomes. For example, of the 15 studies included in their analysis 10 investigated problem behaviour outcomes of former residents. From these studies, one found statistically significant reductions, four found a trend towards improvement, one reported no change, and two found a trend towards increased problem behaviour. More recently, Kim et al. (2001) conducted another literature review and this time found that 10 US studies revealed that former residents experience improvements in problem behaviour after relocation however, only three of these produced statistically significant results after 72 months. Six studies

reported increased levels of problem behaviour by former residents after relocation, including two studies that reported statistically significant increases after 15 and 24 months. Based on their findings, Kim et al. (2001) suggest that community settings are at least as effective as institutions in addressing problem behaviours for people with DD.

These inconsistent findings may be attributable to other factors including the notion that problem behaviours are socially determined therefore, the same behaviour performed by an individual with DD and an individual without DD may be treated differently by those around them (Hill & Bruininks, 1984). Additionally, different behaviours or classes of behaviours are deemed more or less problematic (e.g., aggression versus stereotypy) and therefore research results may be skewed (Lowe et al., 1998). It has also been noted that research results may differ due to inconsistent measurement/observation techniques that are used across studies. Emerson and Hatton (1996) found that information provided by third parties regarding problem behaviour, was associated with no change in frequency after relocation. Conversely, those studies that used direct observations to investigate problem behaviour frequency reported an overall reduction. Studies have also found that level of functioning and time lapse after deinstitutionalization impact rates of problem behaviour. For example, Hemming, Lavender and Pill (1981) conducted a study investigating changes in quality of life for persons with DD who had been moved from an institution to community-based homes in Wales. They found that total problem behaviour increased between transfer and four months and that persons with more severe DD accounted for most of the increase. However, these rates decreased back to baseline nine months after transfer.

Despite the variable impact of deinstitutionalization on problem behaviour exhibited by former residents, reports are relatively consistent in that individuals with DD who have left the institutions may still exhibit these behaviours. Problem behaviours exhibited by individuals with DD would make it difficult to care for, examine and treat them. Therefore, it is reasonable to hypothesize that exhibiting aggression towards others and/or engaging in self-injurious behaviours (SIB) may differentially impact primary health care utilization (Lennox et al., 1997; Levy et al., 2006). For example, a physician may find it more difficult to conduct a proper medical examination with an individual who is consistently engaging in aggressive behaviours, or it may be quite challenging to transport the person to the physician's office without the use of intrusive chemical or mechanical restraints. Therefore, a person with serious behavioural needs may not visit their physician as often as a person who does not engage in these behaviours, or may have less successful visits. This pattern has emerged in previous research on the utilization of other clinical services by persons with DD. For example, Pruncho and McMullen (2004) sought to differentiate patterns and correlates of utilization on an array of community-based services. The participants included adult offspring living with their aging mothers across the US. It was found that those participants characterized as violent were more likely to receive psychological services than those individuals who did not engage in violent behaviour, although the researchers did not specify whether psychological services meant visiting a GP, psychologist, psychiatrist or social worker. Their study included three broad predictive categories: i) predisposing factors, ii) enabling factors, and iii) need factors.

Mental health status and primary health care utilization.

It is difficult to separate problem behaviour and mental health needs into two separate constructs because research has suggested that the presence of a mental illness is based largely upon the presence of problem behaviours (Hemmings, Gravestock, Pickard, & Bouras, 2006; Moss Emerson, Kiernan, Turner, Hatton, & Alborz, 2000). That said, not all problem behaviours indicate the presence of a mental illness. Deb et al. (2001a) investigated the overall rate and types of mental health problems among adults with DD in a community-based population in the UK. They found that the overall rate of schizophrenic illness and phobic disorder was significantly higher in the study's cohort compared to those in the general public. However, they also reported that the rate of functional psychiatric illness, mental illness in which no organic cause is apparent, was similar to that found in the general public at 16%. Further research by Cooper et al. (2007a) supported a portion of Deb et al. (2001a) findings whereby psychosis rates were substantially higher in persons with DD, who were living in communities in the UK, than in the general public. A review by Borthwick-Duffy (1994) confirmed literature inconsistencies by reporting the dual diagnosis prevalence rate as ranging between 10% and 39% depending on the diagnostic criteria used. The studies used in this review were conducted in the Denmark, Sweden, the UK, and the US.

Inconsistencies in the literature could be due to the fact that mental health problems may be defined differently for person with DD than they are for the general public. For example, Gustafsson and Sonnander (2004) investigated the occurrence of mental health problems in persons with DD living in community-based homes in Sweden. They noted that among the most common mental health problems were

aggression and self-injurious behaviour. Often these types of labels/diagnoses are not as prevalent in the general population.

Nottestad, Stromgren and Linaker (2000) had 29 participants take part in a UK study that investigated mental health problems (and behavioural disturbances) before and after deinstitutionalization. Data were collected (using a variety of measures) one year before the participants moved out of the institution and one year after. Mental illness was identified by using the Psychopathology Instrument of Mentally Retarded Adults (PIMRA) during both assessment phases and it was found that the rate of mental illness was no different after the participants had moved out of the institution.

As was previously mentioned mental illness and problem behaviours are closely related as the latter can be symptomatic of mental illness, especially in persons with DD (Fletcher, Loschen, Stavrakaki, & First, 2007). As such, the problem behaviour literature can be used to establish support for the presence of a mental illness as a predictor of health care utilization given that these types of disturbances would require attention from the medical profession; especially if they are placing the individual (or others) at imminent risk.

Psychotropic medication use and primary health care utilization

There is a paucity of research examining the association between psychotropic medication use and primary health care utilization. It has been well documented that persons with DD are among the most medicated in society (Aman, 1984; Aman, Field, & Bridgeman, 1985; Holden & Gitlesen, 2004; Linaker, 1990; Martin & Agran, 1985). Some research has suggested that this phenomenon is a response to high rates of mental illness among persons with DD (Cooper & Bailey, 2001; Cooper, et al., 2007a; Cooper,

Smiley, Morrison, Williamson, & Allan, 2007b) while others suggest that psychoactive medication is primarily prescribed to manage behavioural outbursts (Deb, Thomas, & Bright, 2001b; Molyneux, Emerson, & Caine, 1999). The results of a study by Molyneux et al. (1999) supported both hypotheses. The researchers investigated prescribing practices for 357 persons with DD in three different locales in the UK. Different patterns were identified based on the type of psychoactive medication the participants were currently taking. Surveys were conducted with staff and cross-referenced against health care provider records. Results were acquired from conducting univariate analyses, which were completed in order to identify statistically significant associations between: i) the participant's situation, ii) the locality in which they lived, and iii) the primary method of health services received. Multivariate logical regressions were employed to identify the key variables that predicted whether or not a participant was likely to receive one of three forms of medication. Specifically, they found that prescription of neuroleptic medication was significantly related to the experience of having been deinstitutionalized, presence of problem behaviours, aggression, and having a diagnosed medical condition. Notably, the type of psychoactive medication prescribed was significantly related to whether services were received from a GP or from a psychiatrist. A study conducted in the UK by Robertson et al. (2000) supports the latter hypothesis in that problem behaviours were identified as a key predictor of psychoactive medication use. The researchers administered interviews and questionnaires that were completed by direct-support staff to reveal client information regarding living environment, behaviour, functioning level, presence of a mental illness, and medication prescription regime.

The efficacy of psychotropic medications in the treatment of problem behaviours is uncertain in that Tyrer et al. (2008) compared flexible doses of haloperidol, risperidone, and placebo to investigate the efficacy of antipsychotics in the treatment of aggressive challenging behaviours in individuals with DD. The participants were currently living in one of three locations: Australia, England, or Wales. Eighty-six participants who exhibited aggressive problem behaviours but did not have a diagnosis of psychosis were randomly assigned to one of the three treatment groups. The results of the study indicated that aggressive behaviour decreased substantially with all three treatments by four weeks, with the placebo group revealing the greatest change.

Despite these findings and ongoing concerns about the intrusive nature of psychoactive medications, they remain the most commonly used intervention for the treatment of problem behaviours (Baumeister & Sevin, 1990; Baumeister, Todd, & Sevin, 1993).

Changes in psychotropic medication use in relation to deinstitutionalization. A large percentage of persons with DD are taking psychopharmacological medications (Robertson et al., 2000). A small research base reports differing outcomes with regards to participant medication use before and after deinstitutionalization (Branford, 1996). For example, Hemming et al. (1981) examined 51 adults with severe DD who had moved from a large institution to smaller community residences in Wales. Their results indicated that total problem behaviour and antipsychotic medication prescription increased initially with the former declining at subsequent assessments. Participants who had moved to community residences were prescribed more antipsychotic medications at four, nine and 12 months after relocation than participants who had remained in the institution.

Hemming and colleagues found that former residents who had more severe DD experienced higher antipsychotic medication use compared to participants who had milder DD.

Nottestad and Linaker (2003) investigated psychotropic medication use by persons with DD in Norway before and after deinstitutionalization. They found little change in the number of participants using psychotropic medications and anticonvulsants before and after relocation. These authors also reported that neuroleptics remained the most prescribed category of medication..

More recently, McGillivray and McCabe (2005) conducted a study in Australia that investigated medication use in relation to the type of residential facility a participant was living in. The two participant groups included those measured in 1993 and others measured in 2000. Although the results indicated that the individuals living in institutions from the year 2000 sample received a greater number of medications concurrently than those in the community-based residences, there were no differences in the proportion of individuals prescribed medications with regards to setting. This result directly contrasts the 1993 sample, which revealed medication usage was greater in individuals who were living in institutions. The authors suggested that this change may have reflected the mandatory deinstitutionalization of all residents; the last to come out of the institutions often include those with severe problem behaviours and other issues. Perhaps those already living in the community represented a population that engaged in fewer problem behaviours to begin with. These participants may not have been prescribed psychotropic medications before moving and so would logically be less likely to be prescribed medication afterwards. Although this study did not measure the change in psychotropic

medication use by former residents, it does comment on the differences in medication use in association with living arrangement. This is relevant because it illustrates the equivocal findings in this area of research whereby, differences between the two samples (e.g. 1993, 2000) were reported and potential biases emphasized. Currently in Ontario, all former residents have been moved into the community including those with severe behaviour disturbances, thereby potentially avoiding this bias.

Best practice guidelines have been developed in order to aid professionals in applying the correct dosages and effectively monitoring their clients' use of some medications (de Leon, Greenlee, Barber, Sabaawi, & Singh, 2009). These guidelines included valuable information regarding evidence-based medicine, indications and contraindications, the need for documentation and assessment prior to distribution, and several other relevant issues. Moreover, primary health care guidelines for adults with DD specifically states 'effective observation' is essential for good health (Sullivan et al., 2006). It was suggested that an annual review/checkup be conducted for individuals taking psychotropic medications. Sullivan and his colleagues have suggested that persistent psychotropic medication use by persons with DD requires continuous professional supervision in order to maintain good health (e.g., blood levels). Moreover, frequent monitoring helps ensure effects and side effects are being properly managed. With steady supervision, any medication issues that may arise (e.g. related to polypharmacy) can be promptly attended to and alleviated. The required monitoring of psychotropic medication raises the possibility that psychotropic medication use might predict utilization of health care. Moreover, the relationship between problem behaviour

and psychotropic medication reliance provides further support for its predictive capability.

Polypharmacy and health care utilization.

Establishing best practice guidelines is vital because persons with DD are often prescribed more than one medication (including psychoactive medications) at a time, a term known as polypharmacy (Lott et al., 2004). For these patients, Sullivan et al. (2006) has suggested medications be reviewed every three months in addition to an annual checkup. This has been recommended in part because the biologically active agents within these medications may interact with other medications that, when taken concurrently, may have negative effects on health (de Leon et al., 2009). Lott et al. (2004) investigated longitudinal prescribing patterns for psychoactive medications in persons with DD in community-based settings in California. They found that 62% of the people in the study were being given more than one psychoactive medication. Lewis et al. (2002) investigated the health status and quality of medical services received by adults with DD residing in community-based homes in California. They found that one-third of their participants were taking psychotropic medications, moreover only 24% of those taking psychoactive medications had received a psychiatric consultation meaning that a GP had prescribed their medication. Notably, 12% of their participants were taking more than one antipsychotic. One individual was taking three concurrently. Among those taking anticonvulsants, 39% were taking two different medications while another seven were taking three. Two individuals were taking four medications (not including benzodiazepines).

Potential contraindications due to polypharmacy place persons with DD at risk for health problems (de Leon et al., 2009). Therefore, contact with medical professionals is advisable in the maintenance of good health status (Sullivan et al., 2006). Additionally, given that many persons with DD receive their prescription from a GP (Lewis et al., 2002) and the guidelines established by Sullivan and colleagues recommend frequent visits. It follows that polypharmacy should impact health care utilization although research specifically investigating presence of polypharmacy in relation to health care utilization is limited.

Summary

The commitment to deinstitutionalization has been gaining momentum over the past 50 years, and in Ontario, we have witnessed the end of the era of service provisions for persons with DD by large-scale institutions. This movement may have affected many aspects of its recipients' lives, especially with regard to health care service provisions. Former residents' moves to the community have meant the reallocation of duties to community support agencies and the primary physicians serving the communities. This may present a significant problem, especially in the province of Ontario where a shortage of physicians was noted even before the final stages of deinstitutionalization had been completed (CBC News, 2006).

Elevated prevalence rates of health problem (van Schrojesnstein Lantman-DeValk et al., 2000), mental illness (Deb et al., 2001a; Cooper et al., 2007a), problem behaviours (Feldman et al., 2004), and polypharmacy (Lewis et al., 2002) suggest that unmet health care needs can be particularly detrimental to this population. Despite these elevated needs, the literature has shown that persons with DD sometimes do not receive adequate

health care (Fisher, 2004; Havercamp et al., 2004; van Schrojesnstein Lantman-DeValk et al., 2000). Therefore, investigating the predictive factors that may identify service utilization patterns in Ontario could inform health care policy-makers and could enhance service delivery.

Very few studies have been conducted where individual characteristics were used as predictors of primary health care utilization of former residents. However, the aforementioned literature has examined potential patterns and relationships between utilization and individual characteristics (Hall et al., 2007; Lennox et al., 2003; Levy et al., 2006; Lewis et al., 2002; Pruncho & McMullen, 2004). Throughout this research, participant demographics are consistently reported and are often included in an attempt to explain some health care utilization patterns. Moreover, studies that had investigated various individual characteristics in former residents, independent of health care utilization, have repeatedly highlighted associations between functioning level and mental illness (Cooper & Bailey, 2001); functioning level in relation to psychotropic medication use (Hemming et al., 1981); mental illness in relation to problem behaviour (co-occurrence) (Cooper, et al., 2007b; Hemmings et al., 2006); psychotropic medication use in relation to problem behaviour (Molyneux et al., 1999; Robertson et al., 2000), and health status in relation to age (Hall et al., 2007), functioning level (Patja et al., 2000), and problem behaviour (Davidson et al., 2003).

This study examined the potential predictors of health care utilization in a sample of former residents. Fortunately, enough information exists to conduct a stepwise regression analysis, which was used to analyze this study's dataset. Throughout the literature, age and adaptive functioning level have been consistently used in analyzing

patterns and relationships in health care utilization (Hall et al., 2007; Lennox et al., 2003; Levy et al., 2006). Additionally, research has shown that health status has significantly predicted health care utilization by persons with DD (Hall et al., 2007; Havercamp et al., 2004; Lin et al., 2007). Given the relevance of these three variables in previous research, age, adaptive functioning, and health status comprised the first step of the model, and were added simultaneously. These three variables were expected to account for a significant portion of the variance.

High rates of problem behaviour in conjunction with literature indicating that engaging in this behaviour impacts service utilization (Lennox et al., 1997; Lennox & Kerr, 1997), suggests that this variable may have strong predictive capabilities. Research in primary health care utilization by persons with DD has indicated that psychotropic medication use was a strong predictor of inpatient health care utilization (Lin et al., 2007). Although the current study relates to outpatient services only, this finding remains valuable in informing the stepwise regression model in that it was deemed reasonable to enter psychotropic medication use into the model in the second block. Moreover, Sullivan et al. (2006) suggests that polypharmacy (including psychoactive medications) warrants four medication reviews per year. This suggests that a complex medication regime might predict greater service utilization. Mental health status and its relationship to primary health care utilization was not as prevalent in the literature as the previously noted factors. The higher prevalence of mental health needs in persons with DD, (Cooper & Bailey, 2001; Cooper, et al., 2007a; Cooper, et al., 2007b) warranted the inclusion of this variable in the stepwise model. The second block of variables, therefore, was comprised of problem behaviour, psychotropic medication use, and mental health status.

Objectives

The first objective was to examine and report on current age, adaptive functioning level, health status, level of problem behaviour, mental health status, psychotropic medication use and primary health care utilization in this sample.

The second objective was to examine the relationships between the variables in this sample. Based on the existing literature it was hypothesized that:

a. Age would be positively correlated with health status (Hall et al., 2007). It was expected that as an individual ages the number of identified health conditions (e.g., health status) would increase which consequently represents poor health status.
b. Participants with poorer overall health status would exhibit higher rates of problem behaviour (Davidson et al., 2003).
c. Individuals with higher problem behaviour ratings would be prescribed a higher number of psychotropic medications (Molyneux et al., 1999).
d. Higher problem behaviour ratings would positively correlate with poor mental health status (e.g., presence of a mental illness) (Nottestad et al., 2000).
e. Adaptive functioning level would be negatively correlated with health status (Patja et al., 2000; Tyrer & McGrother, 2009). It was expected that as a participant's score in functioning level decreased (meaning more support is required) the number of identified health conditions would increase (e.g., poorer health status).

The third objective was to determine the extent to which age, functioning level, health status, mental health status, problem behaviour, and psychotropic medication use predict the utilization of primary health care within a multivariate regression model.

Method

Participants

The participants in this study were former residents from the last three institutions in Ontario who had moved into community settings across the province within the last five years. Letters of invitation to participate in the province-wide study[1] were sent to 975 people with DD who had moved out of the Province's institutions, their family members, and their direct-support staff. Consent was received from participants (or substitute decision makers if necessary) and the direct-support staff who provided information for the study. The direct-support staff who provided information on behalf of the participant had known the participant for more than 6 months, in several cases staff had supported the participant since they had moved into the community. This study included data gathered from the first 63 participants that were visited, data collection for the larger study is ongoing.

To recruit participants for this aspect of the study, project coordinators contacted group residences via telephone after consent-for-contact forms were received. They provided further explanation of the study and after setting a tentative date for a research assistant (RA) to go to the home and collect data, sent out information packages and consent forms to the homes. Consent was received from the participating direct-support staff member and the person with DD (or substitute decision maker where applicable) prior to the visit. Direct-support staff and participants (or their substitute decision

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[1] A team of researchers at Brock University lead by principal investigators Dr. Rosemary Condillac, & Dr. Dorothy Griffiths had been commissioned to carry out a study examining the impact of deinstitutionalization on individuals with DD in Ontario. The Facilities Initiative Study is a multi-method study, and these data were collected as part of the Quasi-Longitudinal portion of the study.

makers) had the opportunity to read the consent forms and decide if they would still like to participant. Pending informed consent from all parties, the researcher then visited the home to complete the study's measures. During the RA visit, the participant (former resident) could further assent through cooperating with the RA. If any participant with DD had engaged in behaviours that demonstrated their discomfort with the process, then this would have been interpreted as the individual wanting to withdraw from the study. This did not occur for any measures reported in this study.

Measures and Data Collection Procedures

Measures

Scales of Independent Behaviour- Revised (*SIB-R*; Bruininks, Woodcock, Weatherman & Hill, 1996).

The Scales of Independent Behaviour-Revised is designed to measure functional independence across settings. This norm-referenced questionnaire was completed by the participant's direct-support staff and contains 259 items separated into 14 subscales which are grouped into four adaptive behaviour clusters. These include: social interaction and communication, personal living, community living and motor skills. The SIB-R addresses two broad constructs adaptive behaviour and problem behaviour. Scoring for the two constructs is different. The former are rated based on the extent to which the individual does (or could do) a task completely, without help or supervision. The items that inquire about problem behaviour are rated according to severity and frequency however, for the purposes of this study only the values from the adaptive behaviour construct were used in the dataset because problem behaviour was being assessed by a different measure.

The SIB-R manual refers to several studies that have demonstrated its psychometric properties (Bruininks, et al., 1996). The authors found that median split-half reliabilities for the adaptive behaviour subscale ranged from 0.88-0.98. Test-retest reliability coefficients ranged from 0.96 to 0.97 (Bruininks et al., 1996). The support score that was calculated based on direct-support staff response, was used to determine adaptive functioning level with a higher score meaning less support required.

InterRAI-ID (Martin, Hirdes, Fries, & Smith, 2007).

The InterRAI-ID is a 391 items scale intended to assess individuals with DD across many areas of life. The instrument screens across a wide-range of issues therefore, only a few items are required to identify a potential concern in each area. The 20 domains include: personal information, health service history, cognition, communication, hearing and vision, physical functioning, and self care, physical health medications, skin conditions, oral and nutritional status, psychiatric diagnoses, mental state indicators, life events, behaviour, psychosocial well-being and social supports, education, vocation, recreation, prevention, intervention and home environment. For the purposes of this study, only the diagnostic information and physical health sub-sections were used. The exact count of the number of medical conditions for which a participant was currently receiving active treatment was used to create the health status variable for the regression. The physical health sub-sections provided information to meet the first objective in the study.

The measure was designed specifically for the persons with DD and has been grounded in considerable research on the collection of previous Inter-RAI measures (Martin et al., 2007). Moreover, Martin et al. (2007) tested the measure on 160 community-based residents. Acceptable levels of internal consistency were achieved whereby, Cronbach's alpha ranged from 0.74 to 0.93. This measure was also used for planning purposes while these individuals resided in the institutions and it pivotal to the demonstration of change over time in the larger study.

Behaviour Problems Inventory (*BPI*; Rojahn, 1984).

The *BPI* is a 52 item respondent-based behaviour rating scale instrument for assessing problem behaviour. It contains items specifically pertaining to self- injurious, stereotypic and aggressive/destructive behaviours. All items are rated on a five-point frequency and a three-point severity scale. The BPI is a quality assessment instrument for evaluating problem behaviours in individuals with DD. Several studies have investigated the validity and reliability of this measure, of which the results revealed inter-rater reliability from 0.67 to 0.8 across all subscales. The test-retest reliability was poor for the stereotypy subscale but ranged from 0.67 to 0.7 across all other subscales. Internal consistency was found over most subscales and ranged from 0.6-0.8. However, SIB subscale revealed a low internal consistency of 0.4-0.48. Validity results indicate that the aggressive/destructive subscale had an r value of 0.55, while the self-injurious and stereotypic subscales scored $r = 0.21$ and $r = 0.32$, respectively (Gonzalez et al., 2009; Rojahn, Matson, Lott, Esbensen, & Smalls, 2001). This measure provides information about frequency and severity of problem behaviour. For the purpose of this study, the frequency scores for the self-injury, aggressive/destructive, and stereotypy subscales were added together to create a problem behaviour score, with higher scores meaning more behavioural concerns.

Reiss Screen for Maladaptive Behaviour (*the Reiss Screen*; Reiss, 1988).

The Reiss Screen for Maladaptive Behaviour is a 36 item questionnaire filled out by the participants' direct-support staff. It is designed for individuals with DD who may be experiencing significant mental health problems and are 12 years of age or older. There are eight separate subscales including: aggressive behaviour, autism, psychosis, paranoia,

depression (behavioural), depression (physical), dependent personality disorder, and avoidance personality disorder. The tool also identifies six potential problem behaviours that can be assessed separately. These include drug/alcohol abuse, stealing, overactive, self-injury, sexual problem, and suicidal tendencies. Reiss (1988) reported that the psychopathology dimensions have internal consistency scores ranging between 0.57 and 0.85. The Reiss Screen dimensions have yielded comparable results to other measures investigating the same construct however; the autism and physical depression sub-scales retain lower reliability and validity (Reiss, 1988). For the present study the total score referred to the sum of the 26 items used to derive the cutoff which was established by Reiss (1988). This screening score identified the presence or absence and degree of overall mental health problems in participants.

Current Management Strategies Interview (CMSI; Feldman et al., 2004).

The *CMSI* is an open-ended interview that is designed mainly to determine the treatments being used to treat problem behaviour and the degree to which these are formal or informal. This interview poses questions to inform the interviewer about the i) informant, ii) client, iii) medication, iv) characteristics of the living environment and day program, and iv) emotional and behavioural problems. The medication section of this measure includes questions about whether regular medication review is conducted and by whom. For the purpose of this study the medication section was used to determine participants' total psychotropic medication use. The total number of psychotropic medication use included PRN medications. Despite the common use of anti-convulsant medications for the treatment of behavioural issues (Aman, 1984; McGillivray & McCabe, 2005), this psychoactive medication is also used to manage seizure disorders. Therefore, anti-

convulsants were only counted if the participant was not diagnosed with a seizure disorder.

Health and Mental Health Care Survey (Condillac & Cox, 2010).

The questions included in this survey were based on pre-existing surveys and current literature. Psychometric properties had been established for some of the existing surveys' that comprised the current questionnaire. Specifically, the Stanford Patient Education Research Center posed several questions that were used in the current survey (Lorig et al., 1996). Sections C, D and H from the Developmental Disabilities Profile (DDP-2), which was developed in New York and is a widely used state mandated survey, were also adopted as a part of the current survey (OMRDD, 2007). Many of the other surveys that were found and consulted were comprised of questions that had already been deemed important to include thus, their appearance in these surveys further supported the decision to include them (BRFSS, 2004; GP Patient Survey, 2008). The current survey included seven sections: 1) health care, 2) medical conditions, 3) primary health care access, 4) emergency room information, 5) mental health conditions, 6) mental health care, and 7) mental health care access, the latter two were not pertinent in answering the research questions of this study. The survey can be completed in 30 minutes and some aspects can be answered through reviewing participants' files.

For this study, only the question, "How many medical appointments has the individual attended in the last 12 months?" was used as the measure of health care service utilization. The remainder of the measure will be used by the larger study.

Training

Research Assistants

The individuals serving as Research Assistants (RAs) for this study were trained professionals in the field of DD and graduate students in an applied disability studies program. Prior to visiting participants in their respective homes, the RAs completed three days of training during which thorough explanations of all of the measures and an opportunity to practice were provided.

Procedure

1. Potential participants and/or their direct-support staff were contacted after they had initially submitted a consent-for-contact form. The study was briefly explained to them in simple language and they were asked if they were still interested in participating.
2. If they were still interested, participants were contacted a second time three months later when the study was thoroughly explained to them including risks and benefits. Pending interest, they were sent consent forms and information packages when a tentative appointment had been booked.
3. The information package included: i) the BPI, ii) the Health Care Access and Utilization Survey, iii) the Reiss Screen, and iv) the SIB-R.
4. Upon arriving at the appointment, assent was confirmed by the participant with DD who was participating in the study if a substitute decision maker had provided consent.
5. At the start of the visit, the RA collected the measures that had been completed by the direct-support staff prior to the visit. They also answered any outstanding

questions and/or concerns staff may have had with the pre-completed measures. RA's ensured that all questions on the pre-visit measures had been completed in full.

6. The RA completed the InterRAI-ID with information from the direct-support staff and the clinical file as necessary to complete the measure.
7. Other measures related to the larger study were also completed at this time.

Research Design

As mentioned previously, a stepwise linear regression was performed in order to analyze participant health care service utilization. The total number of physician visits, obtained from section 1-3 of the Health and Mental Health Care Survey. Specifically, this question asked, "How many medical appointments has the individual attended in the past 12 months?". It was completed in the interview with the direct-support staff and cross-referenced to participant case files. The response served as the dependent variable. The six predictors included: (a) age, (b) adaptive functioning, (c) health status, (d) problem behaviour, (e) mental health status (f) psychotropic medication use.

The number of predictors (6), an α of 0.05 and a moderate effect size (0.5) were entered into a post-hoc power analysis for a multiple regression. This power analysis was conducted in order to determine the number of participants required to establish an acceptable level of power (0.8) (Cohen, 1988). The results indicated that 48 participants should be included in the study. However, data for 63 participants was gathered therefore, the power level was increased to 0.92 which is well above the acceptable level (Cohen, 1988). It is important to keep in mind that this was a pilot study and any statistically

significant result, even with a stringent α, was cautiously reported and deemed preliminary.

Results

The total number of participants who had taken part in the study to date was 63 however, direct-support staff for three of them had yet to return completed pre-visit measures thus they were excluded from this analysis. These 3 individuals did not differ from the group in meaningful ways. The following results were based on the final sample of 60 participants who had complete datasets necessary for all analyses.

Description of sample

The first research objective was to examine the current age, adaptive functioning level, health status, problem behaviour, mental health status, psychotropic medication use, and primary health care utilization in this sample. The participants represented a broad geographical/regional range whereby, some resided in urban settings while others resided in rural settings all over Ontario. Descriptive statistics for each variable are presented in Table 1. As seen in Table 1 primary health care utilization had a large range (see Table 1). Notably, 10 individuals accounted for approximately 41% of the visits while the remaining 50 consumed 59% of the visits. The range of visits was quite large with the lowest value at 1, while the highest number of medical appointments was 31. All participants saw a physician at least once per year. 40% had 1-4 appointments, 30% had 5-8 appointments, 13% had 9-12 appointments while 17% had 13 or more appointments.

Participant age varied. Specifically, there were 11 participants (18%) aged 40-49; 35 participants (58%) aged 50-59; 6 participants (10%) aged 60-69; and 6 participants (10%) aged 70-79.

For adaptive functioning level there were two individuals who required the least amount of support on the SIB-R (intermittent), which corresponds to borderline adaptive

behaviour deficits. Five participants scored in the limited support category (mild deficits). Fourteen participants scored in the frequent support category (moderate deficits), while 20 were reported as needing extensive support (severe deficits). Nineteen individuals scored in the highest support level, pervasive (profound deficits).

One individual had nine active medical conditions and one had seven. Thirty-nine participants (65%) had between three and six active medical conditions while nine participants (15%) had between one and two medical conditions. Nine participants (15%) had no medical conditions that were currently being treated

Of the 60 participants, 25 (41%) had a seizure disorder. Eight participants (13%) had gastroesophageal reflux disease (GERD). Fifteen participants (25%) had osteoporosis. Four participants (7%) had asthma and eight (13%) had hypothyroidism. Six individuals (10%) had heart disease complications. With respect to hearing and vision loss, 34 participants (57%) had either severe hearing loss or were deaf and four participants (7%) had severe visual impairment or were blind. In terms of physical impairments, two participants (3%) required a gastric feeding tube for nutrition and 30% of the sample (17 participants) used wheelchairs as their primary mode of locomotion.

Reiss (1988) established cut points to indicate potential presence of a mental illness. As such, a score of 9 or above represents this cut point. Forty-four participants (73%) were below this cut point. Conversely, 16 participants scored 9 or above meaning that 27% of the sample may have a mental illness.

Keeping in mind that anti-convulsant medications prescribed for seizure disorders were not included in the total psychotropic medications used variable, only 6 (10%) of the participants were not taking any psychotropic medications, as per the definition in the

study. Eight percent were taking five or more psychotropic medications concurrently, while 34 (57%) were taking between 2 and 4. This left 25% of the sample taking one psychotropic medication. Of the individuals taking psychotropic medications, 6 (12.5%) were reported to have a mental illness section N2 of the InterRAI-ID. Therefore, 48 participants (80% of the total sample) were taking some form of psychoactive medication, despite the fact that a diagnosis had not been reported by direct-support staff.

The three subscales on the BPI (Rojahn, 1984) included: self-injurious behaviours, stereotyped behaviours, and aggressive/destructive behaviours. Means, standard deviations and ranges are reported in Table 1. All of these distributions showed a majority of participants scoring on the low end across all of the subscales.

Relations between variables

The second research objective addressed the relationships of the proposed predictors in general and tested hypotheses based on findings in the previous literature. The correlation matrix can be found in Table 2 and Table 3. According to the values reported in Table 3, some relationships suggested by previous research were absent. For example, health status was not positively correlated with age or problem behaviour. Problem behaviour did not correlate with health status or total psychotropic medication use and adaptive functioning did not correlate with health status. The hypothesized correlation between problem behaviour and mental health status was apparent. This correlation was moderate and it indicated that as problem behaviour scores increased (e.g., higher frequency of problem behaviour) so did scores on the Reiss Screen (e.g., more indicators of a mental health problem were present). A very small positive correlation between mental health status and total psychotropic medication use was also

present. The relationship here indicated that an increase in scores on the Reiss Screen corresponded with an increase in the number of psychotropic medications used.

Predictors of health care utilization

The third research question examined whether the independent variables predict primary health care utilization by the participants and how much each variable independently contributes to predicting primary health care utilization.

As a reminder, the dependent variable, primary health care utilization represented the number of times the participant had attended a medical appointment in the last 12 months. The independent variables were age, adaptive functioning level, health status, problem behaviours, mental health status and total psychotropic medication use. Age was measured as the participants' age in years on the date of their appointment. Adaptive functioning level was measured by the support score on the SIB-R (Bruininks et al., 1996). Health status was measured by the total number of diagnosed medical conditions for which the participant was currently receiving active treatment. Problem behaviours were measured by summing the frequency scores for the 3 scales of the BPI (Rojahn, 1984). Mental health status was measured by the score on the 26 key items on the Reiss (Reiss, 1988). Finally, total psychotropic medication was measured by counting the number of psychotropic medications the person was currently taking. Seizure medication was only counted as psychotropic if the person did not have a diagnosed seizure disorder.

Prior to completing the regression, the data were reviewed to investigate the assumption of normality and fine-tune the analysis plan.

Distribution and normality analysis

For a full report on the descriptive statistics, including skewness, for each variable see Table 1. The distribution for each variable was positively skewed. However,

skewness was below one for each variable except health status and primary health care utilization. As such, transformations were completed for these two variables only. A square root transformation was conducted to remedy skewness and univariate outliers that were seen as minor problems in the primary health care utilization distribution (see Figure 1 and 2). However, it was decided to continue to use the original data since the slight normality violations were not considered extremely problematic and interpretability is significantly impacted by transformation (Tabachnick & Fidell, 2001). Conversely, the distribution of health status was quite problematic in that it was very positively skewed (see Table 1). A log transformation was used to obtain a relatively normal distribution with acceptable values of skewness and less problematic outliers (see Figure 3 and 4). The mean and standard deviation of log health status was 0.4043 and 0.031, respectively, while skewness was reduced from 1.95 to 0.117. One case was identified as a potential univariate outlier on primary health care utilization (see Figure 5). This participant was not excluded from further analysis yet in the interest of maintaining as large a sample size as possible to promote the integrity of the analysis however, this case was closely monitored in the subsequent analyses.

Examination of regression assumptions

The dataset was then analyzed to determine if multivariate assumptions had been violated whereby a dummy dependent variable (DV), consisting of random numbers, was run against the independent variables (IV) in the set. The results indicate that no linear relationship existed between the dummy DV and the IV's; $R^2 = .028$; $p > .05$.

A simultaneous regression was run to thoroughly examine further multivariate assumptions including: normality, linearity and homoscedasticity. The P-P plot of

regression standardized residuals (see Figure 6) revealed the assumption of linearity was met since the residuals formed an acceptable 'cloud-like' formation around 0 (Tabachnick & Fidell, 2001). The residual values created a nearly normal curve though a slight positive skewness was evident suggesting that the errors of prediction were not equally distributed. This will become important later on. Despite this slight skewness the assumption of normality was met (see Figure 7). A Durbin-Watson value of 2.02 indicated that the residuals were not inclined to have serial correlation with one another (Norusis, 2008). The Pearson-product moment correlation revealed no relationship between any of the variables therefore, multicollinearity was not evident and no discernable relationships existed as was indicated by pre-existing research (see Table 2).

Stepwise linear regression

A stepwise regression was carried out based on the findings of previous studies as discussed in the Summary section. Age, adaptive functioning level, and log (10) health status were all entered into the model simultaneously in the first block. The second block included problem behaviour, mental health status, and total psychiatric medication use which were also entered simultaneously. The resultant linear regression model indicated that these variables did not explain any of the variance, $F(6, 60) = 1.472$; $R^2 = .143$, $p = .206$ (see Table 4). As evident in Table 3, however, mental health status significantly contributed to the unsuccessful model, $\beta = 0.346$; $p = .024$. Casewise diagnostics flagged a single participant as a multivariate outlier, the same one that had been flagged as a univariate outlier. This case was further investigated and was found to have substantial influence over the results in that existing trends in significance (e.g., mental health status contributing to the model) disappeared upon exclusion of the case, $F(6, 59) = .763$; $R =$

.081; p = .602 (see Table 5). The influence that this case had over the regression trends warrants a thorough description of its values. This participant was 48 years old, had visited the physician 31 times in the last 12 months (primary health care utilization), had a value of 15 on problem behaviour, had nine active medical conditions, scored 17 on mental illness, was taking three psychotropic medications and had an adaptive functioning level of 39, meaning extensive support is required. The values that may have contributed to this variables' influence and its status as a multivariate outlier was the unique combination of relatively young age and total medical conditions.

Dichotomizing the dependent variable

The linear model was not significant, in that the variance explained by the predictors in each step in the model did not reach significance, nor did the final model. As was previously mentioned none of the individual coefficients were significant in the model either. Consequently, the variables were examined in order to determine whether a logistic regression would enable the discovery of potential relationships. A logistic regression may be better suited to analyze this dataset because of small number of participants consuming a higher level of service. This indicated the potential existence of two groups in the dataset. As a side, because a logistic regression was now the primary statistical tool being used, the decision to use the original (slightly skewed) primary health care utilization variable, rather than the transformed version, is further validated in that logistic regressions do not require that assumptions of normality be fulfilled (Tabachnick & Fidell, 2001).

The single influential case indicated that a different set of dynamics were present and acting on the relationships between the variables. Additionally, the slight positive

skewness in the dependent variable further supported this notion. The division of the cases into higher and lower usage, the latter being where a majority of the cases fell, was deemed a meaningful distinction. Therefore, it was hypothesized that two groups of health care users existed within the dataset: higher use and lower use. A careful look at the DV's, along with some logical reasoning lead to the creation of cut points for the DV. A group of 10 individuals (17%) who attended 13 or more visits per year accounted for 41% of the medial appointments in this sample. The decision was made to examine this higher use group, as they represented a large portion of the medical appointments used. For the purpose of this analysis, higher usage was defined as 13 visits per year or more (more than monthly) and lower usage was 12 visits per year or less.

Before further analysis, all of the variables were mean centered (see Table 6) in order to aid in Beta weight interpretation and to decrease the risk of multicollinearity (Tabachnick & Fidell, 2001)

Identifying the interaction

In a dataset with a large number of independent variables and a smaller sample size, often examining all pairs of potential interactions is not feasible (Norusis, 2008). As such, it has been recommended to investigate variables whose associations were known based on pre-existing literature. Gathering information through the initial model fitting from the partial and semi-partial coefficients and the DFbeta's has also been recommended in identifying interactions. This reasoning in addition to the presence of a single influential case, lead us to the post-hoc identification of an interaction between mental health status and health status.

Logistic regression

The mean centered IV's were entered in the same order as in the linear multiple regression. A third step was added to account for an interaction between mental illness and health status. A test of the full model with all seven predictors against a constant-only model was statistically reliable, $\chi 2$ (7, N = 60) = 4.121, p = .002, indicating that some of the IV's reliably predicted membership in the higher usage group (see Table 7). Moreover, these IV's accounted for 39% of the variance. A select group of independent variables significantly contributed to the model including: mental illness, total psychotropic medications and the interaction between the mental illness and health status, the latter confirms our interaction hypothesis. An addition finding was that adaptive functioning level achieving marginal significance.

Casewise diagnostics flagged three participants as potential outliers. A logistic regression was performed excluding one participant. This participant was the most extreme outlier in that it had the highest influence values, (Cook's = 2.12); the recommended influence value should be less than one (Norusis, 2008). The removal of this case from the analysis caused several new outliers to be flagged with more extreme influence values. The exclusion of this case also slightly impacted the overall higher usage model whereby variable significance was influenced in that adaptive functioning level went from marginally significant (p = .061) to significant (p = .034) (see Table 8). Upon further investigation of this outlier, as well as the others that were flagged initially, it was discovered that their leverage values did not exceed the recommended cut off (0.3) (Norusis, 2008). Leverage values, in addition to the fact that excluding the highlighted case from the analysis did not change the log-likelihood and resulted in only minor

changes elsewhere in the model; supported the decision to keep this case in the analysis. This decision ensured a more accurate representation of the dataset and retained a higher sample size, which is important for the overall integrity of the analysis.

Among those participants in the higher usage group, this participant's values substantially differed on primary health care utilization and health status, while values on all of the other variables fell around mid-range (see Table 9). Moreover, this case was no longer flagged as an outlier when the logistic regression was performed. As for those participants in the higher usage group, their values in each of the variables represented a significant range, consistent values across any one variable was not apparent. Visual inspection of each variable did not reveal any patterns outright.

Interpreting the ODDS ratios

The ODDS ratios of these significant variables indicated that increasing the interaction variable by one unit the likelihood of being in the higher usage group was 350% greater. The negative relationship between total psychotropic medication use and primary health care utilization was troublesome in that the ODDS of being in the higher usage group was 80% less likely when total psychotropic medication use was increased by one unit. The relationship between mental illness and higher usage group members was such that, when mental illness was altered by one unit the ODDS of being in the higher usage group increased by 30%.

Interaction interpretation

Mental health status and health status were dichotomized. A median split was performed on health status while mental health status was split according to the recommended cut off (nine or above and below nine). A means analysis on the predicted

probability from the model was conducted. The resultant interaction graph indicated that a participant who had one or fewer medical conditions and scored below nine on the Reiss Screen (i.e., low mental health status) had a 20% probability of higher primary health care utilization. A participant with two or more medical conditions and a score of less than nine on the Reiss Screen had a 4% chance of higher primary health care utilization. A participant who had two or more medical conditions and scored higher than nine on the Reiss Screen had a 12% probability of higher primary health care utilization. Lastly, a participant with one or fewer medical conditions and scores above nine on the Reiss Screen (e.g., high mental health score) had a 10% probability of higher primary health care utilization.

Discussion

This study examined health care utilization and its potential predictors in a sample of adults with DD who have moved out of institutions in Ontario within the past 5 years. This discussion will review the results of the study with consideration of the previously published findings, review the strengths and limitations of the study, and suggest ideas for further study in this area.

Descriptive results

Based on pre-existing literature, the distributions and ranges of the sample reflect those of the target population (Baker, 2007; Minihan & Dean, 1990; Nottestad & Linaker, 1999; Tyler & Bourguet, 1997). The participants ranged in age from 40 to 76 years, which is similar to Hundert et al. (2004). The age range in this sample coincides with the 'deinstitutionalization movement' which began to gain momentum in the late 1960's early 1970's (Bruininks, et al., 1981). Recommended service provisions began to change at this time therefore, centralized care was no longer the provision of choice and younger cohorts were provided services through other community-based avenues (Bruininks, et al., 1981). This may explain some of the differences in findings between this study and others that have included participants with a wider range of age.

Adaptive functioning level represented very low to high levels of required support and thereby reflected the range of adaptive functioning expected for former residents (Hundert et al., 2004; Nottestad & Linaker, 2003). Health status varied greatly and was similar to that reported in other studies whereby some individuals had fewer needs and some had many (Hundert et al., 2004; Nottestad & Linaker, 2003). Though the range varied dependent on medical condition, other studies have reported differing levels of

specific medical conditions. For example, Levy et al. (2006) noted only 27.2% of their sample had a diagnosed seizure disorder, while 24.3% had heart disease complications. Osteoporosis and diabetes were documented at 14.6% and 10.7% respectively. Chauhan, Konopantelis, Campbell, Jarrett, and Lester (2010) reported similar levels of heart disease complications at 10% however, thyroid diseases were well above those reported in this study. Gustavson, Umb-Carlsson, and Sonnander (2005) reported hearing impairments at a much lower rate than this study, though severe vision impairments rates were similar.

The range of problem behaviour reported in this sample was similar to other samples of individuals with DD (Hundert et al., 2004; Nottestad et al., 2000). Prevalence of problem behaviour had a large range and was representative of those typically found in this population in that, substantially different levels of frequency are often evident (Davidson, et al., 2003; Hundert, et al., 2004). Mental health status (i.e., presence of a mental illness) was similar to that of previously reported literature (Bhaumik, et al., 2008; Gustafsson & Sonnander, 2004), albeit using different measures. Total psychotropic medication use was similar to that reported in other studies (Nottestad & Linaker, 2003). The finding that 90% of this study's participants were on at least one psychoactive medication, 80% of which did not have a psychological diagnosis, is consistent with some of the literature (Aman, 1984; Lott et al., 2004).

Relations between measures

An interesting finding was the absence of correlations between some of the variables. Based on previous research, there was reason to believe that relationships between these seven variables should emerge (Cooper & Bailey, 2001; Cooper et al., 2007; Davidson et al., 2003; Lennox et al., 2003; Nottestad et al., 2000). More

specifically, it was expected to find a positive correlation between age and health status (Hall et al., 2007) and between problem behaviour and health status (Davidson et al., 2003) neither of which emerged. A positive correlation between problem behaviour and psychotropic medication use was also hypothesized but was not apparent. Moreover, a negative correlation between adaptive functioning level and health status was also hypothesized but was not apparent.

Notably, a moderate positive correlation between problem behaviour and mental health status (Nottestad et al., 2000) was evident, while a very small positive correlation between mental health and total psychotropic medication use (Molyneux et al., 1999) was also found, although it had not been one of the original hypothesized associations. High psychotropic medication use in the sample may have impacted the latter relationship, though it may represent a promising finding in that an individual's mental health needs are being recognized and addressed through the receipt of psychotropic medication.

Prediction of health care utilization

The model building strategy in this study consisted of two consecutive steps: linear regression followed by a logistic regression. Using the logistic regression analysis was beneficial because it enabled prediction of group membership in higher usage and also allowed for the investigation and confirmation of a significant interaction.

This study found that age, health status, adaptive functioning level, and problem behaviour did not predict primary health care utilization; while mental health status, total psychotropic medication use and the interaction between mental health status and health status accounted for 38% percent of the variance in the model. It was expected that age, functioning level and health status would influence primary health care utilization as had

been evident in previous research (Hall et al., 2007; Lennox et al., 2003; Lin et al., 2007). Of specific interest was the non-significant linear regression, as well as the predictors that ended up significantly contributing to the higher usage model because these variables (e.g., mental illness, total psychotropic medication use, and the interaction) were not as supported by the literature with regards to their relationship to primary health care utilization.

Another interesting result was the highly influential case (single participant that was excluded from the linear regression analysis), more specifically the fact that exclusion of this case in the linear regression analysis caused significant trends to disappear. Of further interest, was the fact that this specific case was no longer flagged as an outlier in the logistic regression analysis. Moreover, it fit well in the higher usage group.

The negative relationship between total psychotropic medication use and higher usage group membership that was highlighted by the logistic regression model was troublesome because Sullivan et al. (2006) have recommended more visits to the physician when taking psychotropic medications. This relationship suggests the study's population may be underserved and proper observation of those most in need (e.g., those taking highly intrusive medication) may not be occurring. The positive relationship between the interaction variable and primary health care utilization is logical. First off, the interaction between health status and mental health status is plausible because research with individuals without DD suffering from severe mental illness has reported that these individuals are more inclined to have co-morbid medical conditions than the people with DD or mental illness (Sokal et al., 2004). The fact that health status does not

predict higher usage group membership is puzzling in that it is not until health status (e.g., several medical conditions) is compounded with mental illness does this variable predict higher usage (as per Sokal et al., 2004). It would seem reasonable that someone who does not have a mental illness and/or medical conditions should not need to utilize primary health care as often as someone who is consistently experiencing illness/health problems in addition to struggling with a mental illness. However, the interpretation of the interaction indicated that those with one or fewer medical conditions and scores of lower than nine on the Reiss Screen (absence of a mental health problem) have a greater probability of higher primary health care utilization. The result is notable because an individual who has more medical conditions should be visiting their physician more given that theoretically they may need more support in maintaining good health. For example, they may need more prescription renewals, closer monitoring of an illness, more regular check ups to chart progression of the illness. Conversely, quantity of medical conditions was the IV, rather than quality whereby an individual with an aggressive form of cancer may only have one condition but requires many visits to the physician in order to treat the illness. So, although this individual does not have several medical conditions their one condition requires far more attention than an individual who may have five less problematic illnesses (e.g., common cold, etc). Further investigation of this relationship to determine what exactly it entails and to what extent it impacts health care utilization is warranted.

Potential explanations for our findings

Several factors could have contributed to the outcome of this study. First, it is possible the selection of measures, which was different than other studies, may have

contributed to the outcomes. All of the measures in this study were previously published, with the exception of the Health and Mental Health Care Survey, which was developed locally but relied heavily on questions used in other health care surveys (Developmental Disabilities Profile – 2, n.d; Lewis et al., 2002; Lorig et al., 1996; Pruncho & McMullen, 2004). In addition, the question used to establish the DV was objective. All of the medical appointments attended by participants were documented in consultation reports by the participants' direct-support staff and filed for future reference. Therefore, they were expected to be an accurate report of frequency of visits.

Second, all research assistants underwent several training sessions to become familiar and competent with the proper administration of the measures.

Third, the participant pool of this study was strictly made up of former residents who had been recently moved into the community (up to five years ago), many of whom had spent more than 20 years in a facility. Conversely, much of the previous literature used participant populations from various living situations, from living at home with family, to group home, to institutions (Lin et al., 2007; Minihan & Dean, 1990; Pruncho & McMullen, 2004). In fact, the literature brought attention to this fact and even used it as a differentiating variable (Hall et al., 2007). However, the participants who took part in previous literature had various histories in terms of living arrangements, in that some of the individuals had never lived in an institution while others had etc. Therefore, it is reasonable to believe that the relationships between the independent variables (e.g. age, health status and functioning level) may not impact primary health care utilization in the same fashion in a sample of recent former residents. A possibility exists that the participants in this study were too homogenous in terms of characteristics thus providing

an explanation for the absence of correlations between health status and age, health status and problem behaviour, problem behaviour and psychotropic medication use, and adaptive functioning level and health status. Moreover, Davidson et al. (2003) divided their sample into specific age cohorts, the current study did not do this (in part because of a restricted age range and sample size limitations). Therefore, the differences in correlations were not entirely unexpected.

Fourth, the assumption that the primary health care utilization variable was more accurate than that of previous literature, may have accounted some of the differential outcomes as well. For example, Pruncho & McMullen (2004) included adult participants who lived at home with their aging mothers, who are not required to keep documentation of health care in the same manner as paid care providers. Pruncho and McMullen (2004) acknowledged this shortcoming, this is mentioned because it provides a potential explanation for this study's results. Admittedly these researchers dealt with a slightly different group of participants. However, their results were used to provide information regarding this study's predictors because they were investigating patterns of service utilization in the community by persons with DD. Given that the amount of literature in this area of research is limited, using what is available (while recognizing its limitations) is a viable option. Other studies that included participants from an array of settings (including former residents) were used as further support for the predictors and yet, the results did not reflect those reported in these studies (Hall et al., 2007; Lennox et al., 2003; Lewis et al., 2002; Levy et al., 2006). Clearly there are other variables, and potentially other interactions, at play when the participants include only former residents. Using a uniform sample population may have removed some of the confounding effects

of unknown variables influencing primary health care utilization that was present in previous studies.

Fifth, previous was largely based out of the UK and US, which do not operate under the same universal health care plan that Ontarians with disabilities have access to. As such, type of medical insurance (e.g., Medicaid) was used as a predictor in some models and may further explain the differences between the current model and those in previous studies. The influence that this variable has had in other models was removed and any confounds (which may or may not have influenced age, health status and adaptive functioning level) are also excluded. This may provide further explanation as to the differences in this study's outcomes versus pre-existing literature.

Finally, the Facilities Initiative did not occur without opposition. Many families had concerns, specifically around access to adequate health care services (Tabatabainia, 2003). The families were aware that their loved ones were receiving centralized medical services in the institution and Ontario was (and is) experiencing a shortage of physicians. As such, during the planning process, efforts were made to address these concerns by using person centered planning and providing funding to ensure that primary medical care availability and other needed services were available for former residents in their new communities (Galambos, 1999). The results of this study suggest that this was in fact the case; all former residents had some contact with a physician; with 75% of them seeing a physician 4 or more times in the last year. This predetermined level of service may account for the different pattern of predictors in health care utilization compared to previous research with broader samples of people with DD.

Study strengths

Specific strengths of this study included the use of an objective measure to gather information for the dependent variable, which was often noted as a weakness in other literature. Second, the former residents came from three different institutions, unlike previous samples that typically follow cohorts from one facility. Third, the participants lived across the province of Ontario, in urban centers, smaller cities, and rural settings so different geographical locations were adequately represented. Fourth, the general public visit their physician an average of 3.7 times per year and 24% of them do not attend any medical appointments in a year (Chan & Shultz, 2005). Conversely, the participants in this study had an average of 7.7 medical visits per year and every participant attended at least one medical appointment in the last 12 months. This finding directly contrasts some of the literature that has indicated a paucity of primary health care utilization in the community-based health care by persons with DD (Fisher, 2004). Moreover, it supports the notion that former residents can utilize community-based health care. The reason for this may be due to the person-centered planning that preceded participants' relocation into community residences (Galambos, 1999). This finding may also serve to address the concerns raised by former residents' family members who were worried about decentralized health care provisions. Finally, the fact that 45 (75%) participants met Sullivan et al. (2006) recommendations of quarterly medical reviews (pending polypharmacy) is promising in that best practice guidelines were being adhered to which could be interpreted, albeit cautiously, that the health care needs of this study's participants were being met.

Study limitations

Although the study had some strengths, its limitations must be highlighted as well. First, inaccuracies in the data could have been introduced due to a majority of the information being collected by proxy . Unfortunately this could not be prevented as the majority of participants lacked the communication skills necessary to provide the information; this flaw is common among research conducted with people with DD. Second, there may have been a response bias, in that the group was amongst the first to volunteer for the study which may make them different from those who volunteer at a later date. A letter of invitation was distributed and individuals, their support staff, and/or, families responded accordingly. Third, the sample size did not permit the investigation of other possible relationships/interactions that could account for the remaining variance in the model. Third, unexplored items such as "time out of the institution" may be impacting the predictive capabilities of these variables. For example, Hemming et al. (1981) reported on problem behaviour after deinstitutionalization and found that four months after relocation resulted in participants' acquisition of new problem behaviours and/or increased incidences of problem behaviours. After nine months these levels returned to baseline. The participants in this study had been living in the community for at least one year, some of them had been living in the community for up to five years by the time a RA came to visit them. Given the sample size, adequate statistical power did not support the inclusion of time out of the institution and its potential impact on primary health care utilization. Fourth, age range was restricted even though average age in this sample represents what is typical for former residents in Ontario. The age range in this study contrasts the literature used to support its hypotheses

where age ranges were much broader and may have contributed to the absence of a correlation between age and health. Finally, the measure used to create the mental health status variable (the Reiss Screen) may have introduced inaccuracies into the data. The former residents in this study were quite elderly and a majority of the participants fell in the severe to profound adaptive behaviour deficits level. As a result, the Reiss Screen may not have been sensitive enough to identifying mental illness within this population. This is because older individuals may not present mental illness in the same way (e.g., through aggression) that younger individual with DD do (Jacobson, 1982; Hove & Havik, 2010) and many of the questions on the Reiss Screen inquire about aggression and other outward problem behaviour rather than more reserved indicators of mental health issues. Moreover, the literature has also noted that those with significant adaptive behaviour deficits often present with more medical conditions (Patja et al., 2000) and this could limit the topography and severity with which problem behaviours are emitted.

Future Research

This study has unveiled some possible areas for future study. First, it would be of great interest to increase the sample size substantially to increase the reliability of the higher usage model and further investigate the relationship between health status and mental illness. Second, as the higher usage model accounted for only 38% of the variance, a model that includes potential predictors (e.g. time out of institution; health care access issues) could provide further insight into this important issue. Finally, if possible, a study that measured utilization based on actual health care utilization (as derived from access to health insurance data base in Ontario) could reveal not only the number of visits but the complexity of care received, which might fit the model better.

Conclusions

Overall, the results were quite promising in terms of community-based services' ability to provide for former residents. Moreover, this study directly addressed the need to examine which individual characteristics of former residents operate in combination with one another or independently in predicting health care utilization. This gap was identified by Hayden et al. (2005) who had conducted a literature review on existing research investigating health care utilization by persons with DD living in the community. Several factors (e.g., psychotropic medication use, mental health status, and the interaction of health status and mental health status) were identified as significant predictors of higher primary health care utilization by former residents which adds much needed information to the current limited research base. Direct-support staff , administrators and policy-makers need adequate knowledge of primary health care utilization patterns in order to provide the best care possible for former residents.

This study represents some of the first preliminary findings from the Facilities Initiative in Ontario and will lead the way for further investigation into health care utilization in the community by former residents.

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Table 1

Descriptive Values of Independent and Dependent Variables

Variables	*n*	*M*	*SD*	*Max.*	*Min.*	*Skewness*	*SE*
Total medical appointments	60	7.65	5.99	31	1	1.64	0.31
Age	60	55.58	1.07	77.00	40.00	0.83	0.31
Adaptive functioning level	60	34.70	2.07	80.00	1.00	0.45	0.31
Health status	60	1.95	0.23	9.00	0.00	1.95	0.31
Mental health status	60	6.60	0.81	22.00	0.00	0.89	0.31
Total psychotropic medication use	60	2.35	0.20	6.00	0.00	0.56	0.31
Problem behaviour	60	22.28	2.13	56.00	0.00	0.59	0.31
BPI Self-injurious behaviour frequency	60	4.51	0.62	20.00	0.00	-	-
BPI Self-injurious behaviour severity	60	3.17	0.433	13.00	0.00	-	-
BPI Stereotyped behaviour frequency	60	13.59	1.54	40.00	0.00	-	-
BPI Stereotyped behaviour severity	60	6.85	0.86	31.00	0.00	-	-
BPI Aggressive/Destructive behaviour frequency	60	3.61	0.62	22.00	0.00	-	-
BPI Aggressive/Destructive behaviour severity	60	3.53	0.58	15.00	0.00	-	-

Table 2

Correlations between Dependent and Independent Variables (N = 60)

Variable	1	2	3	4	5	6	7
1.Age	-	-0.04	0.09	-0.07	-0.09	-0.03	0.05
2. Adaptive functioning level		-	-0.02	-0.24*	-0.12	-0.03	-0.01
3. Log (10) Health status			-	-0.01	0.07	-0.04	0.21*
4. Problem behaviour				-	0.47**	0.22*	-0.06
5. Mental health status					-	0.28*	0.22*
6. Total psychotropic medication use						-	-0.09
7. Primary health care utilization							-

*p < .05.**p<.001.

Table 3

Correlations between Variables Excluding Influential Case

Variable	1	2	3	4	5	6	7
1.Age	-	-0.04	0.15	-0.08	-0.06	-0.02	0.13
2. Adaptive functioning level		-	-0.27*	-0.24	-0.13	-0.05	-0.04
3. Log (10) Health status			-	0.01	0.00	-0.06	0.06
4. Problem behaviour				-	0.49**	0.22*	-0.04
5. Mental health status					-	0.27*	0.14
6. Total psychotropic medication use						-	-0.13
7. Primary health care utilization							-

*p < .05. **p<.001

Table 4

Initial Linear Regression (N=60)

Variable	*B*	*SE B*	*B*
Step 1			
Age	0.02	0.09	0.03
Adaptive functioning level	0.02	0.05	0.04
Log (10) Health status	5.56	3.40	0.22
Step 2			
Age	0.03	0.09	0.05
Adaptive functioning level	0.09	0.05	0.02
Log(10) Health status	4.58	3.34	0.18
Problem behaviour	-0.07	0.05	-0.19
Mental health status	0.332	0.14	0.35
Total psychotropic medication use	-0.49	0.51	-0.13

Note. $R^2 = .05$ for Step 1; $\Delta R^2 = .09$ for Step 2.

*p < .05. **p<.001.

Table 5

Linear Regression Excluding Influential Case (N=59)

Variable	*B*	*SE B*	*B*
Step 1			
Age	0.08	0.08	0.12
Adaptive functioning level	-0.01	0.05	-0.02
Log (10) Health status	0.73	3.21	0.03
Step 2			
Age	0.08	0.08	0.12
Adaptive functioning level	-0.01	0.05	-0.03
Log(10) Health status	0.43	3.21	0.02
Problem behaviour	-0.04	0.05	-0.13
Mental health status	0.21	0.13	0.325
Total psychotropic medication use	-0.56	0.46	-0.17

Note. $R^2 = .02$ for Step 1; $\Delta R^2 = .06$ for Step 2.

*p < .05. **p<.001.

Table 6

Mean Centered Descriptive Values of Independent and Dependent Variables

Variable	*n*	*M*	*SD*	*Max.*	*Min.*	*Skewness*	*SE*
Age	60	5.58	1.09	27.10	10.00	0.83	0.31
Adaptive functioning level	60	0.00	2.07	45.30	-33.70	0.45	0.31
Health status	60	0.00	0.03	0.60	-0.40	0.12	0.31
Problem behaviour	60	-0.06	2.13	33.70	22.30	0.59	0.31
Mental health status	60	0.00	0.81	15.40	-6.60	0.89	0.31
Total psychotropic medication use	60	2.35	0.20	3.65	-2.35	0.59	0.31
Primary health care utilization	60	0.00	0.77	23.35	-6.65	1.64	0.31

*p < .05. **p<.001.

Table 7

Mean Centered Logistic Regression Including Interaction (N=60)

Variable	*B*	*SE B*	Wald	Exp (B)
Step 1				
MC Age	-0.01	0.04	0.02	1.00
MC Adaptive functioning level	-0.01	0.02	0.22	0.99
MC Log (10) Health status	1.45	1.54	0.88	4.25
Step 2				
MC Age	-0.00	0.05	0.00	1.00
MC Adaptive functioning level	-0.04	0.03	1.55	0.96
MC Log(10) Health status	0.97	1.75	0.31	2.65
MC Problem behaviour	-0.05	0.04	1.90	0.95
MC Mental health status	0.25	0.09	8.23	1.28
MC Psychotropic medication use	-1.11	0.49	5.20	0.33
Step 3				
MC Age	0.10	0.71	1.77	1.10
MC Adaptive functioning level	-0.09	0.05	3.50	0.91
MC Log (10) Health status	-0.42	3.32	0.02	0.66
MC Problem behaviour	-0.67	0.05	1.72	0.94
MC Mental health status	0.31	0.32	5.15	1.37*

Note: $R^2 = .01$ for Block 1; $\Delta R^2 = .22$ for Block 2

*p < .05. **p < .001.

Table 7 (continued).

Mean Centered Logistic Regression Including Interaction (N=60)

Variable	*B*	*SE B*	Wald	Exp (B)
MC Total psychotropic medication use	-1.75	0.78	5.09	0.17*
MC Mental health status * MC Log (10) Health status	1.52	0.65	5.37	4.55*

Note: $\Delta R^2 = .16$ for Block 3

*p < 0.05.** p < .001.

Table 8

Mean Centered Logistic Regression Including Interaction Excluding Flagged Case (N=59)

Variable	*B*	*SE B*	Wald	Exp (B)
Step 1				
MC Age	0.01	0.04	0.05	1.00
MC Adaptive functioning level	-0.02	0.03	0.52	0.98
MC Log (10) Health status	0.20	1.70	0.01	1.22
Step 2				
MC Age	0.01	0.05	0.07	1.01
MC Adaptive functioning level	-0.05	0.03	2.01	0.96
MC Log(10) Health status	-0.58	2.16	0.07	0.56
MC Problem behaviour	-0.04	0.04	0.98	0.97
MC Mental health status	0.23	0.08	6.66	1.25*
MC Total psychotropic	-1.28	0.55	5.50	0.28*
medication use				
Block 3				
MC Age	0.06	0.09	0.53	1.07
MC Adaptive functioning level	-0.15	0.07	4.47	0.86*
MC Log (10) Health status	-0.98	3.77	0.07	0.38
MC Problem behaviour	-0.09	0.07	2.04	0.91
MC Mental health status	0.51	0.22	5.50	1.67*

Note: $R^2 = .02$ *for Block 1;* $\Delta R^2 = .23$ *for Block 2*

$p < .05$. $p < .001$.

Table 8 (continued).

Mean Centered Logistic Regression Including Interaction Excluding Flagged Case (N=59)

Variable	*B*	*SE B*	Wald	Exp (B)
MC Total psychotropic medication use	-2.01	0.85	5.65	0.13*
MC Mental health status* MC Log (10) Health status	2.16	0.88	6.07	8.67*

Note: $\Delta R^2 = .13$ for Block 3

**p < .05. **p < .001.

Table 9

Descriptive Values of Independent and Dependent Variables in Higher Usage Group

	n	*M*	*SD*	*Max.*	*Min.*	*Skewness*	*SE*
Age	10	55.53	2.87	72.00	40.00	0.83	0.69
Adaptive functioning level	10	31.60	3.81	58.00	20.00	1.08	0.69
Health status	10	2.60	0.82	9.00	0.00	1.99	0.69
Problem behaviour:	10	20.70	6.06	56.00	0.00	0.59	0.69
Mental health status	10	6.60	0.81	22.00	0.00	0.89	0.69
Total psychotropic medication use	10	1.50	0.34	3.00	0.00	0.00	0.69
Mental health status * Log (10) Total health status	10	331.90	123.26	1120.00	0.00	0.98	0.69
Primary health care utilization	10	18.70	1.61	31.00	13.00	1.63	0.69

Figure Captions

Figure 1. Primary health care utilization distribution. The distribution curve of the variable primary health care utilization reveals a slightly positive skewness.

Figure 2. Primary health care utilization square root distribution. The distribution curve of the variable primary health care utilization reveals positive skewness.

Figure 3. Health status distribution. The distribution of the variable health status is positively skewed.

Figure 4. Health status log (10) distribution. The log transformation of health status performed to remedy positive skewness and normalize the distribution.

Figure 5. Boxplot distribution of primary health care utilization. The boxplot of primary health care utilization emphasizes that flagged univariate outliers are not too extreme.

Figure 6. P-P plot for assumption of normality test. A normal P-P plot of regression standardized residuals of linear regression was used in the initial regression analysis to investigate whether the assumption of normality had been met.

Figure 7. Histogram for assumption of normality test. Initial evaluation of regression assumption of normality by plotting the frequency of the standardized residuals of predictor variables to ensure residuals are normally distributed before including investigating regression outcomes.

Figure 1. Primary health care utilization distribution

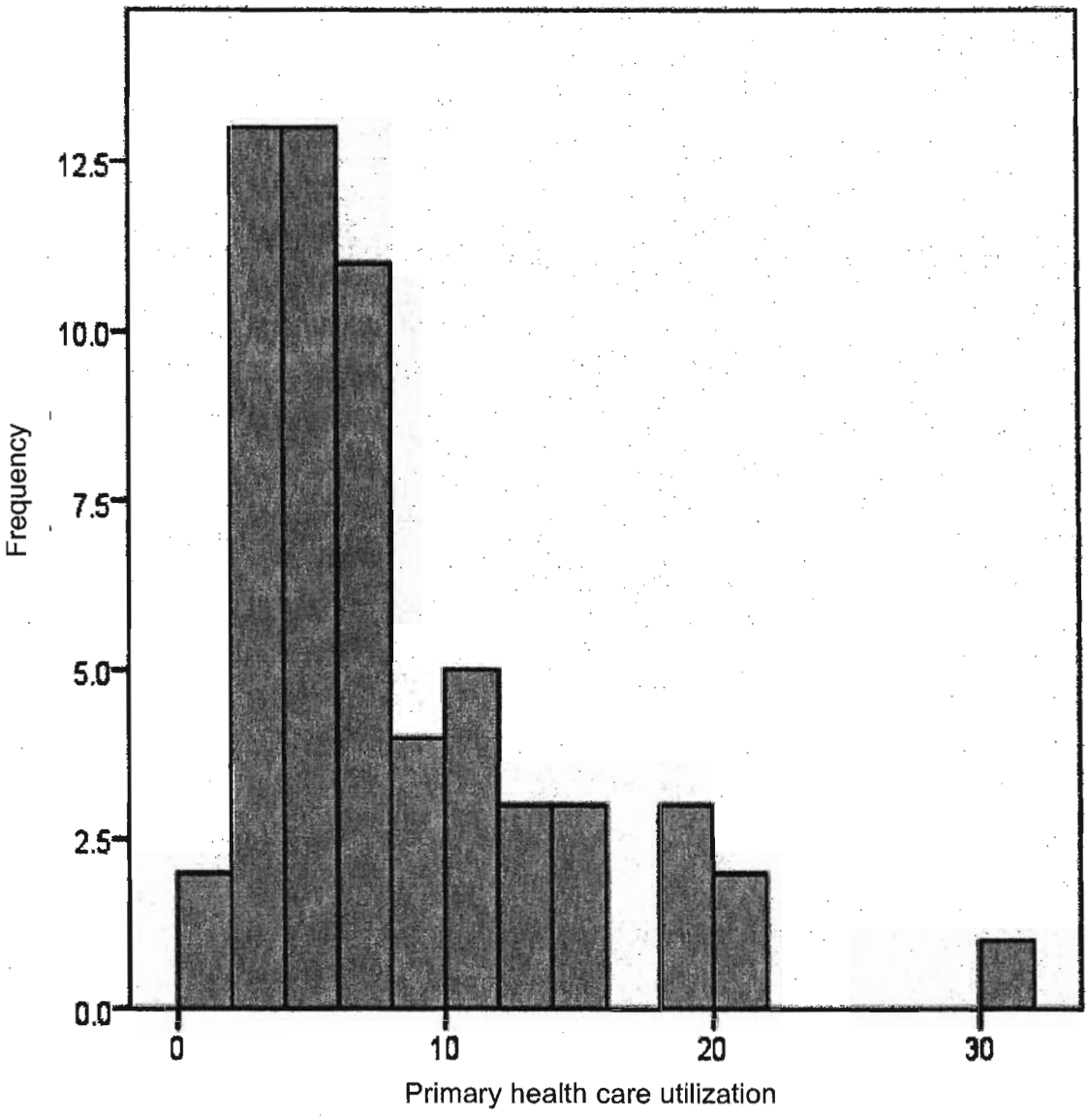

Figure 2. Primary health care utilization square root distribution

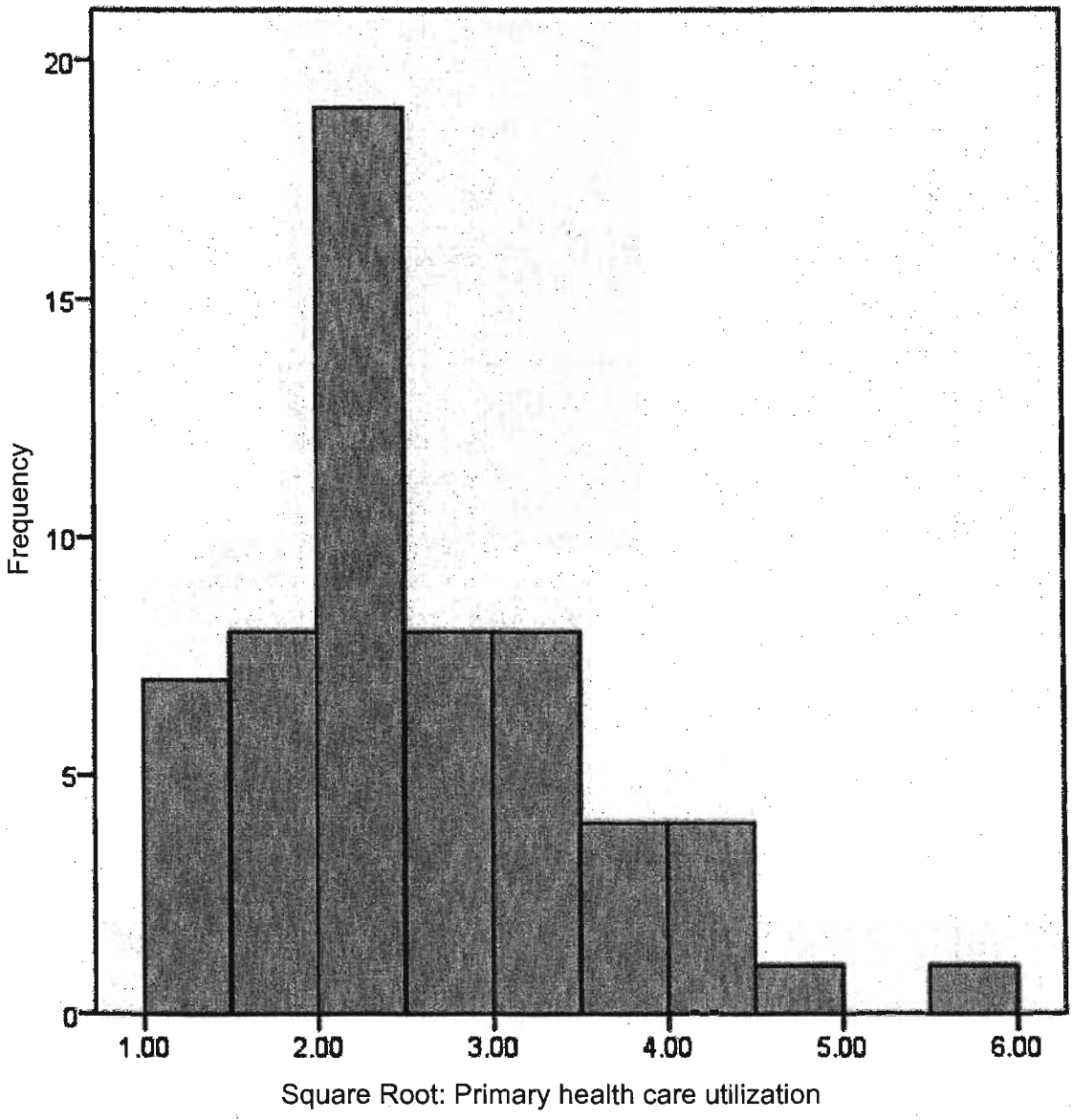

Figure 3. Health status distribution

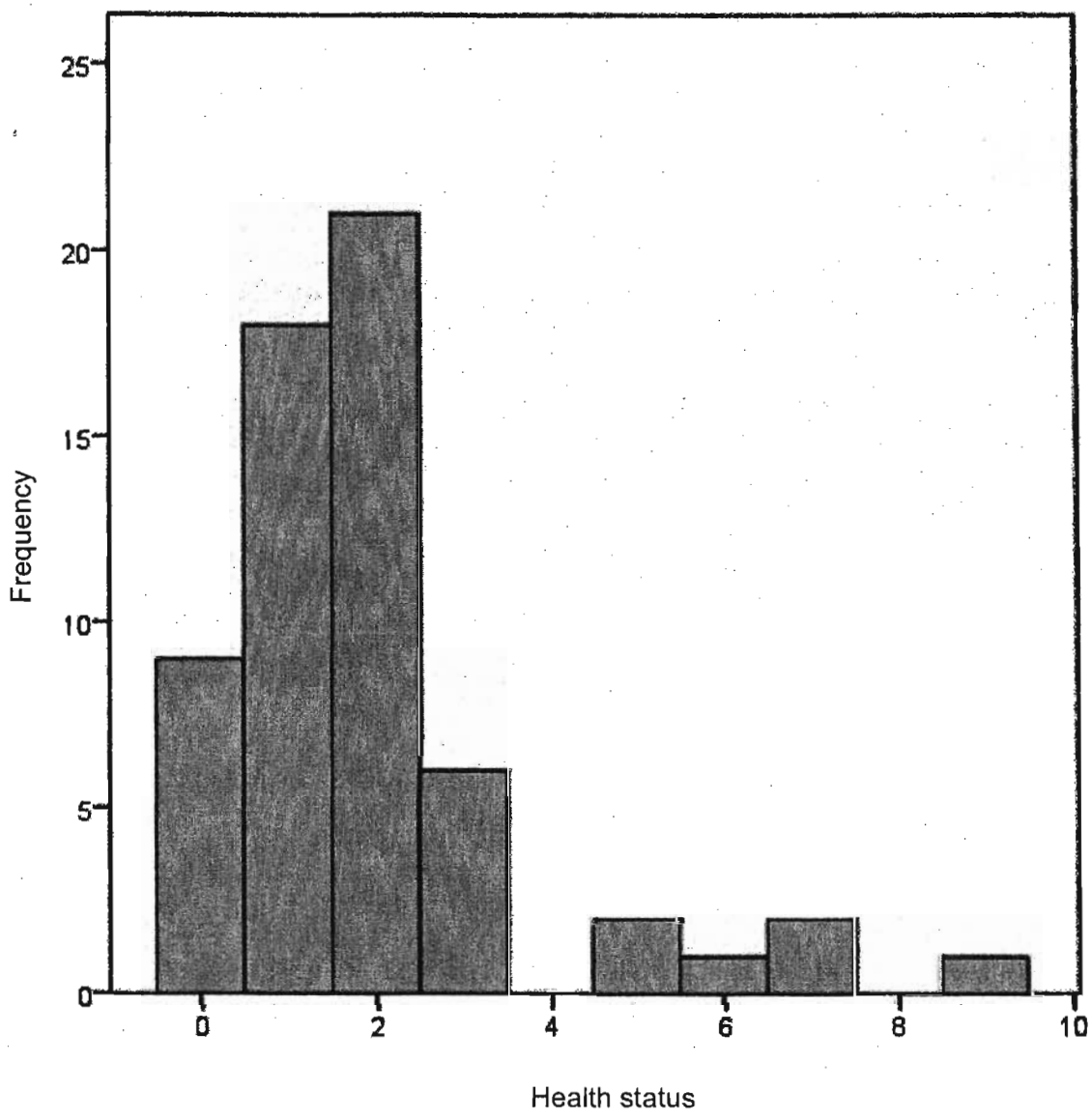

Figure 4. Health status log (10) distribution.

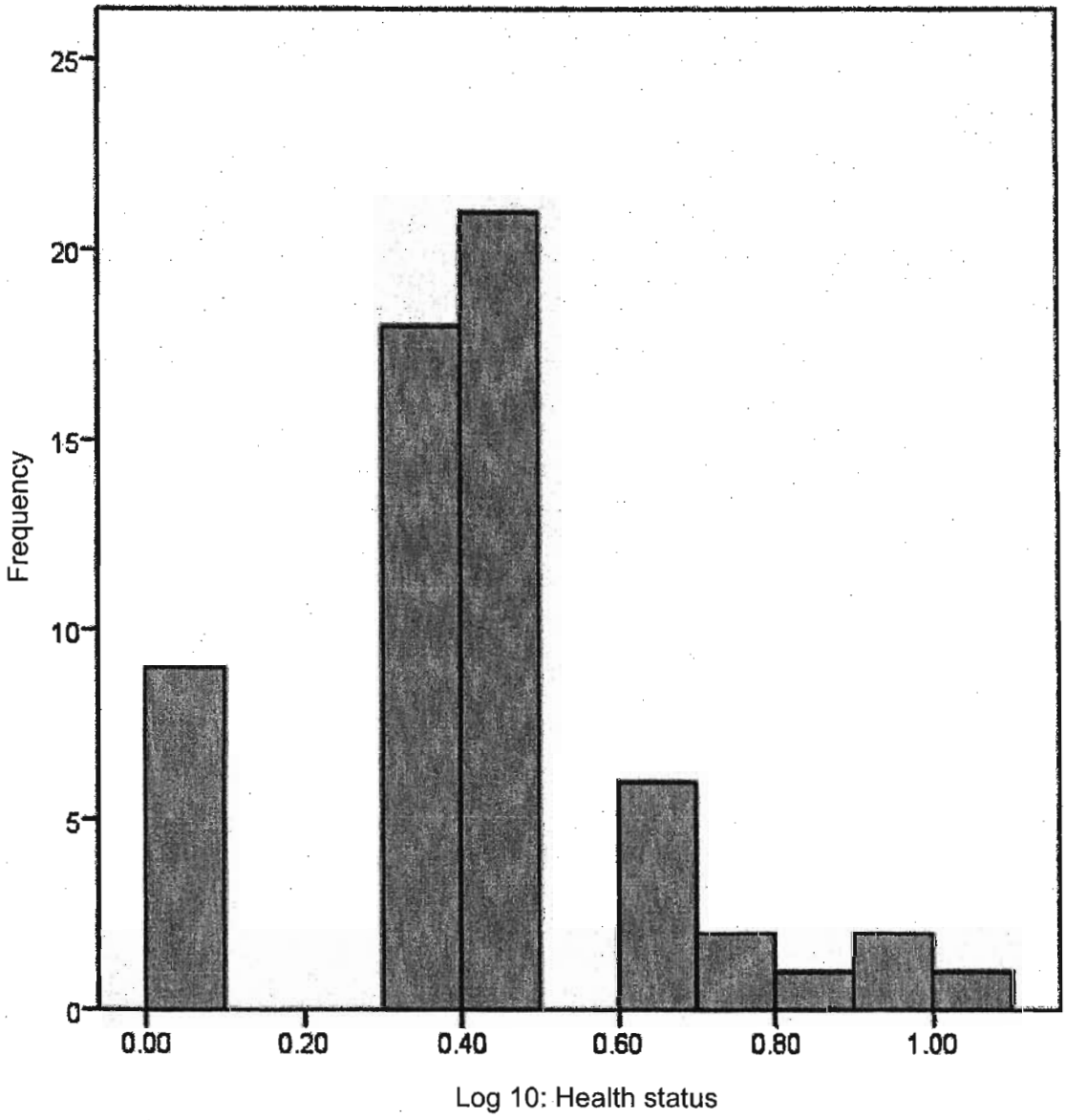

Figure 5. Boxplot distribution of primary health care utilization

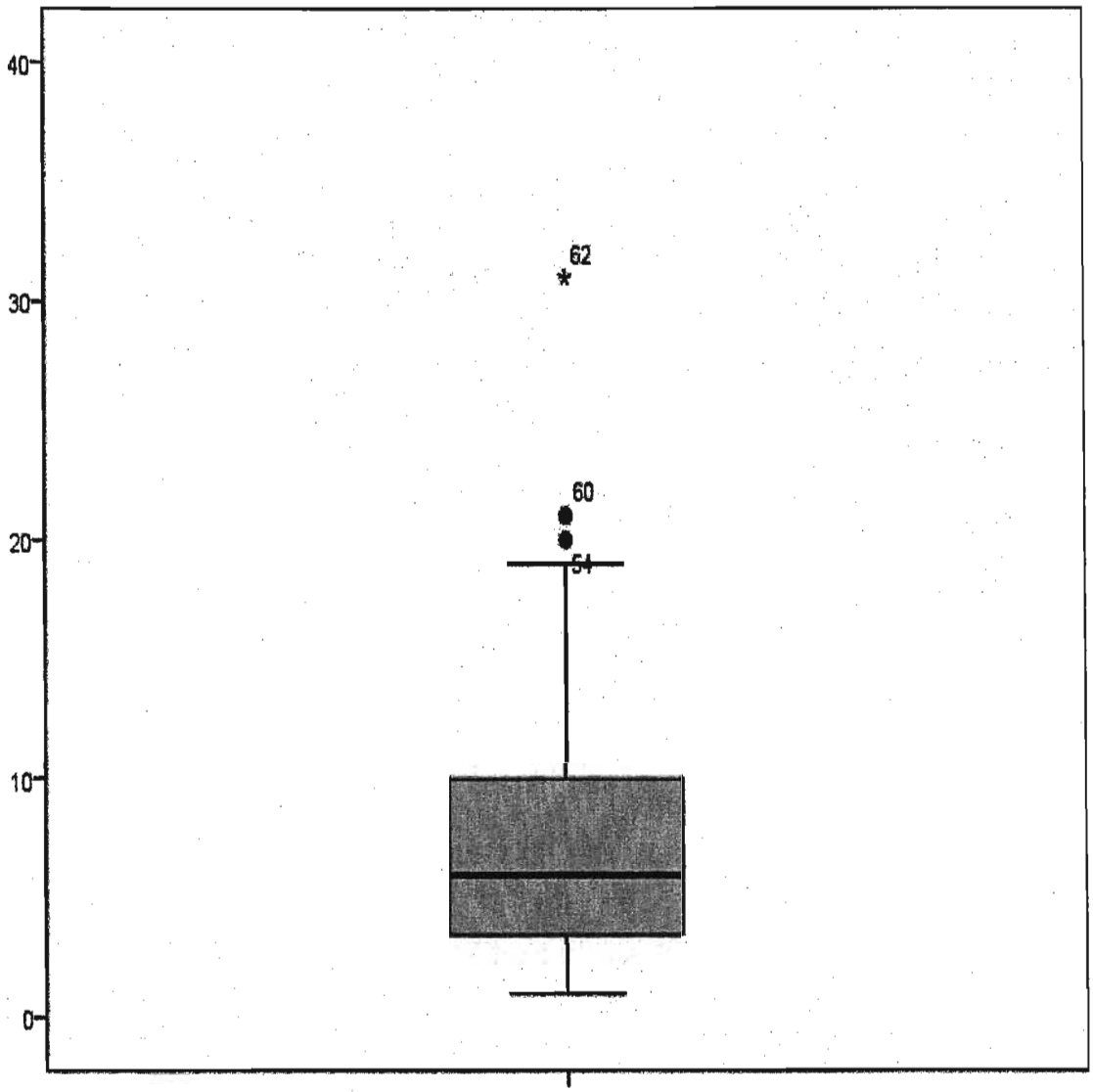

Figure 6. P-P plot for assumption of normality test.

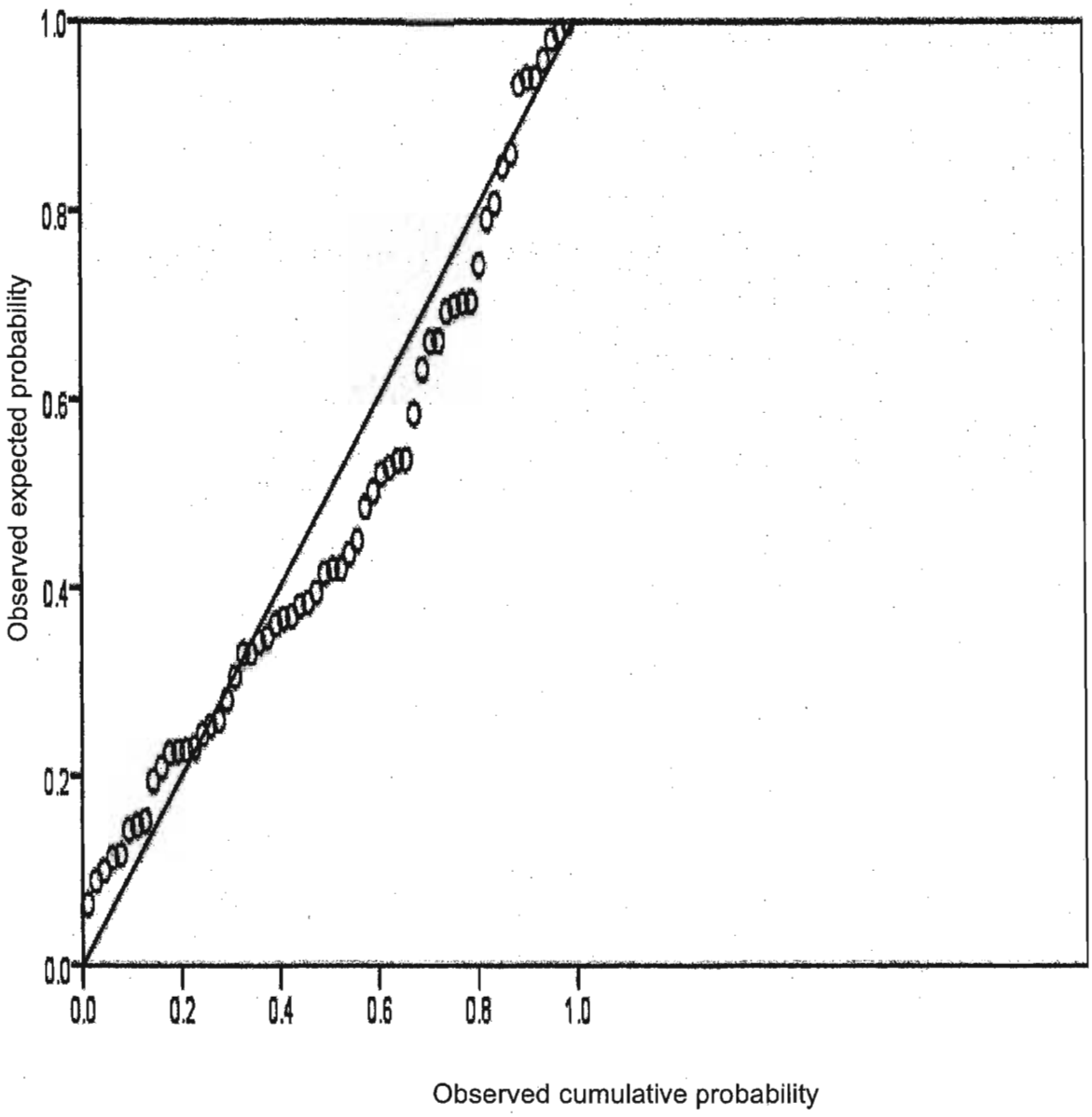

Figure 7. Histogram for assumption of normality test.